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**VOICES TO REMEMBER:
PERSONS' AND FAMILY MEMBERS'
EXPERIENCES OF LIVING WITH
NEUROCOGNITIVE DISORDERS AND
RELATED SYMPTOMS**

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VOICES TO REMEMBER:

Persons' and family members' experiences of living with neurocognitive disorders and related symptoms THESIS FOR DOCTORAL DEGREE (Ph.D.)

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To my dear sister Letitia, kind, brave and vibrant

ABSTRACT

Persons with cognitive impairment are often encouraged by society and family to seek a cognitive assessment and receive a timely dementia diagnosis (dementia is also known as a major neurocognitive disorder). A cognitive assessment can help recognise possible reversible causes of cognitive symptoms and/or the presence of other neurocognitive disorders or diseases. It can take up to three years from the time a person experiences the first cognitive symptom, to contacting health care and referral for a cognitive assessment. Most persons with dementia develop neuropsychiatric symptoms such as; hallucinations, apathy, agitation during the course of the disease. The presence of these symptoms often impacts negatively on the person and family members and are trigger factors for admissions to residential care. These symptoms are often under-identified in health care. Knowledge gaps exist about persons' experiences of a cognitive assessment and neuropsychiatric symptoms early in the disease trajectory. Many persons with dementia reside in their own homes with a family member. Further knowledge is required regarding the person's and family members' experiences of the situation. The aim of this doctoral thesis was to describe older persons' and family members' experiences of living with neurocognitive disorders and related symptoms in a community setting.

Study I an interview study with 23 persons with cognitive impairment who had commenced a cognitive assessment. An interpretive description data-analysis was carried out. The findings are presented under four themes; Conflicting views between the person and their family about severity of the situation, Identifying the presence of neuropsychiatric symptoms, Compensating strategies used to remember and Worries about self and what the future holds.

Study II a follow-up interview study (to study I) with 18 persons who had completed a cognitive assessment in a polyclinical setting. Interpretive description was used to analyse the interview data. The findings formed two main themes. The first theme focuses on levels of trust in the process and the second theme about attempts to understand and make sense of a neurocognitive diagnosis.

Study III an interview study with 14 spouses to partners with dementia and neuropsychiatric symptoms. The persons with dementia were reported as having between five to eight neuropsychiatric symptoms at the same time. The theme "Living on the edge, lacking support and time for self" represented the findings of this study.

Study IV an interview study with nine family members to persons with frontotemporal dementia and neuropsychiatric symptoms. Persons with frontotemporal dementia were reported as having between four to eight co-existing neuropsychiatric symptoms. Two themes emerged from the data; "Living with a well-known stranger and Coping and overstepping social norms."

LIST OF SCIENTIFIC PAPERS

- I. Tyrrell, M., Religa, D., Fossum, B., Hedman, R., Skovdahl, K., & Hillerås, P. (2020). Embarking on a memory assessment – Voices of older persons living with memory impairment. *Accepted for publication*.
- II. Tyrrell, M., Hedman, R., Fossum, B., Skovdahl, K., Religa, D., & Hillerås, P. (2020). Feeling valued versus abandoned – Voices of persons who have completed a cognitive assessment. *Manuscript is submitted and under review*.
- III. Tyrrell, M., Hillerås, P., Skovdahl, K., Fossum, B., & Religa, D., (2017). Voices of spouses living with partners with neuropsychiatric symptoms related to dementia. *Dementia*, 18(3), 903-919.
- IV. Tyrrell, M., Fossum, B., Skovdahl, K., Religa, D. & Hillerås, P., (2019). Living with a well-known stranger: Voices of family members to older persons with frontotemporal dementia. *International Journal of Older People Nursing*. Ooe 12264.

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LIST OF ABBREVIATIONS

AD	Alzheimer's disease
BPSD	Behavioural and psychological symptoms of dementia
BPS	Biopsychosocial model
DICE	Describe, investigate, create and evaluate
DLB	Dementia of Lewy Body
DSM-5	Diagnostic and statistical manual of mental disorders, 5th edition
FTD	Frontotemporal dementia
GP	General practitioner
ICD	International classification of disease
ICN	International Council of Nurses
ID	Interpretive Description
MCI	Mild Cognitive Impairment
MMSE	Mini-Mental State Examination
NBHW	National board of health welfare
NPI	Neuropsychiatric Inventory
NPI-NH	Neuropsychiatric Inventory – Nursing Home version
NPS	Neuropsychiatric symptoms
PC	Person-centred
PCC	Person-centred care
SDG	Sustainable development goals
UN	United Nations
VaD	Vascular dementia
WHO	World Health Organisation

PREFACE

Both my late parents worked in Dublin's largest psychiatric hospital, our family life was seasoned and enriched by the people of this hospital, both residents and staff. I started my career in health care working on a 30-bedded long Florence Nightingale like dormitory, for older persons with dementia and other mental health disorders, it was a locked ward. Nursing care provided was mostly task-orientated and followed a strict military like schedule, each resident was bathed once a week which included nail care and weighing. The "bowel book" was filled in every evening by a junior member of nursing staff. Working 12-hour shifts the physical care provided was excellent however far remote from a person-centred approach which is recommended in health care today. I was fascinated back then how residents who often appeared apathetic and disorientated seemed to come "to life" to recite prayers or poetry and sing along to songs. I knew back then that there was a lot more to learn about persons with dementia and care provided. The year was 1985. After spending some years working in England, Ireland and United Arab Emirates as a registered nurse, I moved to Sweden with my family in 1995. As a registered nurse, with specialist education in psychiatry and elderly care, I have worked mainly with older persons with cognitive impairment in different contexts in Sweden. A lecture by Gunilla Armaneus Björlin, Geriatrician, about persons with behavioural and psychological symptoms of dementia [BPSD] was the starting ground for this research project. As a staff nurse working with older persons, I cared for many persons with dementia admitted for social planning due to the presence of BPSD. Family members, I encountered, were often near breaking point after caring for their loved one with dementia prior to admission. In many cases, family members had not sought support prior to admission instead tried to manage the situation themselves. Admission to hospital for the person with dementia was often viewed as a last resort by family overshadowed by guilt and loss.

1 INTRODUCTION

There is a push in society for persons who experience cognitive impairment to seek an assessment and receive a diagnosis. According to epidemiological studies up to 20 percent of persons over 65 years in a community setting have neurocognitive disorders. Neurocognitive disorders range from mild cognitive impairment to dementia, however not all have a diagnosis. A person's daily life, and their families, are often affected significantly in the presence of a neurocognitive disorder and related symptoms. Over 50 percent of persons with dementia in Sweden reside in their own home. Many persons with advanced dementia who still reside in their own dwelling live with a family member. Some countries are adopting policies focusing on the person with dementia remaining in the community, postponing admissions to residential care. This in turn requires dementia-specific health care and social support, in order to help to maintain the person's and family member's quality of life. This doctoral thesis documents the voices of persons' and family members' experiences of living with neurocognitive disorders in their own homes.

2 BACKGROUND

In this doctoral thesis neurocognitive disorders referred to range from mild cognitive impairment to dementia. This chapter begins with a brief account of global and national perspectives on dementia followed by a presentation of concepts and processes associated with making a neurocognitive diagnosis. In the final section of this chapter different perspectives concerning living with neurocognitive disorders are presented.

2.1 GLOBAL AND NATIONAL PERSPECTIVES ON DEMENTIA

Worldwide there are approximately 47 million persons living with dementia (World Health Organisation [WHO], 2019). The risk for a person to develop dementia increases with age, with eight percent of all persons 65 years and older and almost fifty percent of persons 90 years and older develop dementia. Population projections estimate that 82 million persons globally in 2030 will have developed dementia and 152 million persons by the year 2050 (WHO, 2019). Each year between 20,000 and 25,000 persons develop dementia in Sweden with roughly the same number of persons dying with the disease (National Board of Health and Welfare, [NBHW], 2018).

Dementia is a medical condition describing a complex group of symptoms associated with cognitive deficit in multiple domains and functional deterioration (American Academy of Neurology, 2016; Arrighi, McLaughlin & Leibman, 2010) in parallel with behavioural and psychological symptoms (Kales, Gitlin & Lyketsos, 2015). The WHO declared dementia a public health priority due to the high global prevalence, socio-economic impact on the

person, family members and communities and related stigma and social segregation (WHO, 2012).

In Sweden, the National Guidelines for Dementia Care provides recommendations for decision-makers to allocate resources responding to the needs of persons with dementia and their families. The aim of the guidelines is for organisations to promote high quality care and improve health outcomes for persons concerned. As dementia is not for now a curable condition, the goals of health- and social care are to facilitate daily life and contribute to the person's quality of life. Person-centred care [PCC] is the recommended approach to care. The guidelines also focus on persons who experience cognitive symptoms and recommend them to seek a cognitive assessment in primary care. Upon receiving a dementia diagnosis, regular follow-up support and care should be available for the person to help meet medical and psychosocial support needs (NBHW, 2017).

2.2 COGNITION

Gårdenfors (2011) describes cognition as the mental activities involved in gathering and processing information. A person's cognition is composed of the following domains: language abilities, spatial abilities, memory, attention, cognitive speed, executive abilities (planning, organisation, evaluation of thoughts and actions) perception and motor abilities (Almqvist, 2011; Harada, Natalson & Triebel, 2013). As with the rest of the human body the human brain also experiences changes during the aging process, with deterioration in the number of neuronal synapses in the cerebral cortex and a reduction in brain size occurs (Purves et al., 2018). In testing a person's cognitive domains, stimuli must be first perceived, information is then processed, followed by the provision of a response. Sensory perception and speed of processing stimuli decreases during the ageing process (Salthouse, 2010). Both internal and external factors can impact on a person's cognition e.g. the person's age, level of education, mood, social activities, alcohol consumption and comorbidities (Kim & Park, 2017a).

The term memory impairment is commonly used in referring to cognitive decline and is the most common domain investigated in older persons seeking an assessment for cognitive impairment (Rabin et al., 2015). Reisberg and Gauthier (2008) recommend the use of the term cognition instead of memory due to the complexity of the field of cognition, since memory is just one of several cognitive domains.

2.3 COGNITIVE ASSESSMENT

Persons with cognitive impairment are often encouraged by society and family to receive a timely neurocognitive diagnosis, to facilitate future care planning and access support services, treatment and information (Prorok, Horgan & Seitz, 2013; Alzheimer's Association, 2019).

An early diagnosis can also help identify reversible causes of cognitive impairment (Borson et al., 2013). Family members often encourage the person with cognitive impairment to seek a cognitive assessment for validation of symptoms they observe, and to gain an understanding of the situation (Morgan et al., 2015). Primary health care is often the first point of contact for persons with cognitive impairment and their families (Bunn et al., 2012; Galvin & Sadowsky, 2012).

Persons over 65 years seldom seek health care explicitly for memory impairment (Begum et al., 2012). Persons with early stage dementia can experience cognitive symptoms as a threat to autonomy, sense of security and an erosion of their role in society (Steeman et al., 2006) and a life overshadowed with uncertainty (Campbell et al., 2016). From the time the person experiences initial symptoms of cognitive impairment, it can take on average 35 months before they are referred for assessment (Koskas et al., 2018). Fears of stigmatisation and social isolation (Phillipson et al., 2015) plus a feeling of being disregarded, misattributing causes and conceding to memory impairment are some factors which affect delays in contacting health care (Perry-Young, Owen, Kelly & Owens, 2018).

Fowler et al. (2015) identified that approximately one half of older persons, with initial cognitive testing results indicative of dementia, refused to continue with investigations during a cognitive assessment. High stigma scores and living alone were related factors (Fowler et al., 2015). According to Magin et al. (2016) most persons want to know if they have Alzheimer's disease [AD], and have a greater acceptance of non-invasive testing as opposed to invasive testing to determine a diagnosis. Persons identified as having a high risk of receiving an AD diagnosis were more reluctant to an assessment, as were persons with lower levels of education (Magin et al., 2016).

In line with the dementia care guidelines (NBHW, 2017), a basic cognitive assessment is offered in primary health to persons experiencing cognitive impairment. The assessment includes the following: A full medical history, interviews with family members (if relevant), physical and psychological assessments and structured assessments of function and activity capacity are carried out with the person. Thereafter cognitive performance is tested using the Mini-Mental State Examination [MMSE] (Folstein, Folstein & McHugh, 1975), a tool used to screen a person's level of global function. A clock-test is also carried out, a tool used to evaluate the person's ability in clock setting and reading (Tuokko, Hadjistavropoulos, Miller & Beattie, 1992). To complete the person's basic assessment a blood analysis is carried out and a computed tomography of the brain (NBHW, 2017).

If the basic assessment is not conclusive in identifying the cause of cognitive impairment, the person is then referred to a specialist cognitive clinic for further investigations. The following are examples of investigations and assessments carried out in specialist clinics; neuropsychological testing, magnetic resonance imaging, and/or position emission tomography scan of the person's brain (NBHW, 2017).

2.4 CRITERIA FOR DIAGNOSING NEUROCOGNITIVE DISORDERS

In diagnosing neurocognitive disorders international criteria manuals are employed, such as the International Classification of Diseases [ICD], which is a guideline for diagnostic and is published by the WHO (1993). The ICD-10 is presently still in use (2020) however, a new version ICD-11 was published in 2018. In diagnosing Frontotemporal dementia [FTD] the Lund-Manchester Consensus (1994) is recommended.

The Diagnostic and Statistical Manual of Mental Disorders fifth edition [DSM-5] is published by the American Psychiatric Association [APA] (2013). The DSM-5 is a manual for assessment and diagnosis of mental health disorders and does not include recommendations for treatment. It provides a common language for physicians and helps increase the reliability in making a diagnosis (APA, 2013). The DSM-5 classifies cognitive impairment and dementias under major and mild neurocognitive disorders. In DSM-5, AD is renamed as Major or Mild Neurocognitive Disorder Due to AD. FTD is classified as Major or Mild Frontotemporal Neurocognitive Disorder. Vascular dementia [VaD] and Lewy Body dementia as Major or Mild Neurocognitive Disorder with Lewy Bodies Major or Mild Vascular Neurocognitive Disorder (APA, 2013). The cognitive domains in focus in the DSM-5 are; Perception-motor function, language, learning and memory, executive function, complex attention and social cognition (APA, 2013).

Both the cognitive assessment and diagnostic processes have a bio-medical approach in helping to identify the presence of a neurocognitive disorder. Sabat (2008) recognises the importance of having a bio-medical model in distinguishing areas of the person's brain that are damaged, explaining symptoms experienced and disease course. However, aspects of the person's situation that cannot be explained include the person's reactions, feelings and perceptions of their situation with dementia (Sabat, 2008). With a view to gain a better understanding of older persons' experiences of participating in a cognitive assessment and receiving a diagnosis further research is needed (Samsi et al., 2014; Robinson et al., 2011).

2.5 MILD COGNITIVE IMPAIRMENT

Mild cognitive impairment [MCI] is a broad term and is used to describe a person's cognitive decline. Cognitive decline is identified through neurological assessment and observing if the

person's independent daily activities are compromised (Albert et al., 2011). In DSM-5, MCI is described as a syndrome and termed as a Minor Neurocognitive Disorder (APA, 2013). MCI as a term was first developed by Flicker, Ferris and Reisberg (1991) and was initially presented to describe persons receiving a score of three or less on the Reisberg Global Deterioration Scale (Reisberg, Ferris, de Leon & Cook, 1982). The scores obtained by the person on the scale are based on clinical assessments and judgments. Scores range from one (no cognitive impairment) to seven (representing a vegetative state as a result of dementia). The term MCI was adopted to explain a period where cognition was no longer normal for the person in relation to age and daily function and was not extensive enough to warrant a diagnosis of dementia (Smith & Bondi, 2013; Petersen et al., 2014).

According to the American Academy of Neurology Guidelines (Petersen et al., 2018) between 10 to 20 percent of older persons (over 65 years) residing in the community have MCI. Persons with MCI have a three times higher risk of developing AD two to five years earlier than their peers. There are multiple underlying causes of MCI, however some are reversible and can be due to e.g. side-effects of medications, sleep apnoea, depression or other conditions. The guidelines recommend that physicians use validated tools in assessing the person's cognition, check for modifiable risk-factors, the presence of behavioural symptoms etc. and monitor the person's cognition over time (Petersen et al., 2018).

2.6 DEMENTIA

Dementia is a general term used to describe a range of conditions which include a global interference of the intellectual capacity of a person as a result of disease to the brain (Marcusson, Blennow, Skoog & Wallin, 2011). According to Haaksma et al. (2020) the survival rate for a person with dementia is on average five years from the point of diagnosis. The most common types of dementia are AD, VaD, FTD and dementia with Lewy Body [DLB] (Valkanova & Ebmeier, 2014). Dementia disease is broadly divided up into three groups: Neurodegenerative disorders, VaD and other types of dementia disease.

2.6.1 Neurodegenerative disorders

Neurodegenerative disorders are caused by degenerative processes attributed to cell death and the inability of cell regeneration with general neuronal structural and functional discrepancies. These conditions develop as a result of genetic predisposition, or acquired with known and unknown origins (Hussain, Zubair, Purcell & Shabab, 2018). The areas of the brain affected depend on the causes of the diseases such as: AD, FTD and DLB. In AD the degeneration begins in the hippocampus and in FTD deterioration begins in the fronto- and temporal lobes of the brain (Marcusson, Blennow, Skoog & Wallin, 2011). In DLB abnormal deposits of Lewy Body proteins (ubiquitin and alpha-synuclein) are found in the sub-cortical nuclei of the person's brain (Budson & Kowell, 2013, p. 132). There are three distinct

features in DLB: shifting cognitive impairment, visual hallucinations and extrapyramidal symptoms. The clinical features of DLB overlap with Parkinson's disease (Budson & Kowell, 2013).

AD is the most common form of dementia (Fiest et al., 2016; Prince et al., 2016), it was first described by Alois Alzheimer after his examination of Auguste Deter in 1901. AD is a neurodegenerative disorder which is characterised by the presence and accumulation of extracellular amyloid beta, which forms plaques and intracellular build-up of hyperphosphorylated tau proteins forming neurofibrillary tangles. The presence of this pathology causes a progressive loss of neurons and cerebral atrophy (Scheltens et al., 2016). The onset of AD is gradual with symptoms worsening over time (Hussain, Zubair, Purcell & Shabab, 2018).

FTD, previously known as Pick's disease, is a neurodegenerative disorder affecting the frontal and temporal lobes of the brain causing atrophy and neuronal decay. The disease has an insidious onset, with gradual progression resulting in behaviour and language decline for the person concerned with memory relatively preserved (Hodges, 2010). The difference between FTD and other types of dementia is that the person's memory often remains intact, however gradual changes occur in the person's behaviour and language (Everhart, Watson, Bickel & Stephenson, 2015). Coyle-Gilchrist et al. (2016) identified a peak prevalence of FTD between the ages of 65 to 69 years. There are three main clinical types of FTD, Behavioural variant FTD (most common form of FTD), Semantic dementia and Progressive non-fluent aphasia (Hodges, 2010). Frontotemporal dementia is often underdiagnosed due to similarities of symptoms to several psychiatric disorders (Lanata & Miller, 2016).

2.6.2 Vascular dementia

VaD is regarded as the second most common form of dementia after AD with approximately 15 percent of all dementia classified as VaD (O'Brien & Thomas, 2015). Cerebrovascular disease is the primary cause of VaD. Cerebrovascular disease "refers to the diseased state of blood vessels in the brain, both large and small, in which vascular function is disrupted by a number of pathologies" (Budson & Kowell, 2013, p. 105). Disruptions in the blood flow to the person's brain results in interference in brain function (Nazarko, 2019), pathologies referred to are large and small vessel stroke and other pathology seen in the blood vessels (Budson & Kowell, 2013). VaD is also known as vascular cognitive disorder. The neuropathy can vary from multifocal and/or diffuse lesions in the brain. Cerebral vascular lesions are often seen in persons with AD and other brain diseases (Jellinger, 2008).

2.6.3 Other types of dementia diseases

There are other types of dementia which have differing causes such as; virus infections (e.g. Human Immunodeficiency Virus), Creutzfeldt-Jakob or as a result of neurological diseases such as Parkinson's disease (Marcusson, Blennor, Skoog & Wallin, 2011).

2.7 NEUROPSYCHIATRIC SYMPTOMS IN NEUROCOGNITIVE DISORDERS

The term neuropsychiatric symptoms [NPS] (Cummings et al., 1994) is used interchangeably with the term; Behavioural and Psychological Symptoms of Dementia [BPSD]. BPSD was established as a consensus term by the International Psychogeriatric Association (Finkel, Costa & Silva, 1996). In this doctoral thesis NPS is the term of choice and refers to the following symptoms; hallucinations, delusions, agitation/aggression, dysphoria/depression, anxiety, euphoria, apathy, disinhibition, irritability/lability, aberrant motor behaviour, sleep and night-time abnormal behaviour and appetite and eating change (Cummings et al., 1994).

Persons with MCI and dementia experience both cognitive and non-cognitive symptoms. Examples of cognitive symptoms are; memory impairment and reduction of executive function (described under DSM-5). Non-cognitive symptoms are defined as behavioural and psychological symptoms (Brodarty, Draper & Low, 2003). The majority (up to 90 per cent) of persons with dementia develop behavioural and personality changes (NPS) during the disease trajectory (Fauth & Gibbins, 2014; NBHW, 2017). It is common that persons with dementia have more than one co-existing NPS (Youn et al., 2011).

The presence of NPS has an overwhelming impact on persons with dementia and families, triggering acute admissions to general hospitals, morbidity, increased mortality (Van den Wijngaart et al., 2007; Kales et al., 2005; Okura & Langua, 2011) and admissions to residential care (Toot et al., 2017; Leroi, Voulgari, Breitner, & Lyketsos, 2003; Van den Wijngaart et al., 2007; Kales et al., 2005; Okura & Langua, 2011). During the disease trajectory, the presence of NPS fluctuates (Tschanz et al., 2011) accelerates and rarely disappears (Peters et al., 2015; Steinberg et al., 2008). The quality of life for both the person with dementia and their carer are affected negatively by NPS increasing suffering for those concerned (Fauth & Gibbins, 2014; Lee et al., 2004; Froleich et al., 2009; Shankar et al., 2014).

Although NPS is recognised as an integral part of life for a person with dementia (Livingston et al., 2017) symptoms are often under-identified during the standard cognitive assessment process in specialist clinics (Braun et al., 2019; Halpern et al., 2019). Lack of attempts to identify the presence of NPS can deny the possibility of access to psychosocial interventions and possible pharmacological treatment, which can reduce the symptoms and improve the person's quality of life (Woolley et al., 2011).

One third of the costs for society in providing care, treatment and management for persons with dementia is attributed to the management of NPS (Murman et al., 2002). Earlier research on NPS has mainly focused on persons in residential settings with few research studies focusing on persons from the point of diagnosis. Persons in the early stages of dementia can also experience NPS (Lövheim, Sandman, Karlson & Gustafsson, 2008; Osland-Vik-Mo, Gill, Ballard & Aarsland, 2018). In studies carried out by Thompson et al. (2010) and Fernández-Martínez et al. (2008) no significant differences in levels of NPS were identified in relation to the type of dementia diagnosis the person had.

The Swedish National Guidelines for Dementia Care recommend that health care and social care offer structured follow up assessment, care and interventions for persons with dementia experiencing NPS (NBHW, 2017).

2.8 ASSESSING THE PRESENCE OF NEUROPSYCHIATRIC SYMPTOMS

There are multiple contributing factors causing NPS for persons with dementia such as underlying neurodegeneration, unmet needs (physical and psychosocial), caregiving factors including environmental causes and interactions with others (Kales, Gitlin & Lyketsos, 2015). For persons with dementia and NPS a PCC approach is beneficial, as it considers and incorporates a variety of unique factors specific to the person when planning care (Kim & Park, 2017b; Cohen-Mansfield, 2000).

There are numerous assessment tools used in caring for persons with dementia. When assessing the person's psychological and behavioural symptoms, the following three tools are mainly used (Sheehan, 2012): The Cohen-Mansfield Inventory (1986) an assessment tool for carers to assess a range of behaviours from verbal aggression to sexual advances. The second assessment tool is BEHAVE-AD (Reisberg et al., 1987) and covers several types of disruptive behaviours and psychotic symptoms a person with dementia may have. The third assessment tool is the Neuropsychiatric Inventory [NPI], a questionnaire devised by Cummings et al. (1994) which presents 12 symptoms (previously mentioned). If a symptom is identified specifics about the symptom are ranked in terms of frequency, severity for the person with dementia and finally distress experienced by the carer in the situation. Cummings et al. (1994) requires that the person completing the NPI (on behalf of the person with dementia) has good current knowledge of the person with dementia and their daily and nightly activities. The NPI is a widely used assessment tool in research (Sheehan, 2012).

In Sweden, a symptom-based questionnaire CIMP-QUEST (Åstrand, Rolstad & Wallin, 2010) is used as part of a cognitive assessment in some specialist cognitive clinics. The questions in CIMP-QUEST are grouped into categories which hypothetically represent regions of the brain e.g. frontal lobe, occipital lobe. There are further questions in the questionnaire regarding observations of memory impairment and psychological and

behavioural symptoms. CIMP-QUEST is generally completed by family members of persons with dementia (with their consent).

Kales et al. (2014) developed a framework describing four steps which assists in structuring the assessment and management in caring for a person with NPS. The four steps identified are; Describe, Investigate, Create and Evaluate [DICE]. This framework helps identify underlying causes of NPS and together with a PCC approach integrate appropriate interventions. The DICE model has mainly been described in residential settings however, an ongoing study by Eikelboom et al. (2019) assesses its use for persons enrolled at a specialist cognitive clinic. To provide a comprehensive assessment of persons with dementia it is important to have a holistic approach and assess the person's biological, psychosocial and environmental conditions (Cohen-Mansfield, 2000; Spector & Orrell, 2010).

Tchalla et al. (2018) suggest that the burden of NPS symptoms is a predictor of cognitive decline. It is also common that persons with MCI develop NPS however, little research has been carried out in the area. Identifying and treating NPS can help increase the quality of life for the person with a possible impact on reducing cognitive decline (Sachs-Ericsson & Blazer, 2015).

2.9 PERSPECTIVE TAKING IN NEUROCOGNITIVE DISORDERS

2.9.1 Human rights and legislation in Sweden

In this paragraph the main laws regarding health care and social services for persons residing in their own homes in Sweden are presented in brief.

In Sweden health care provision for persons living in their home is regulated by the Health and Medical Services Act [*Hälso- och sjukvårdslag*] (2017:30) alongside the Social Services Act [*Socialtjänstlag*] (2001:454). These laws govern the provision of care for persons requiring long or short-term care in Sweden. The Health and Medical Services Act (2017:30) governs the responsibility of county councils and municipalities in safeguarding the rights of persons living in Sweden to access good health care. This law also specifies that persons are free to register with a chosen general practitioner [GP] or have one allocated to them in a primary health care (private or public). In circumstances where the person requires input from both health care and social services a collaborative care and support plan is created for the person concerned. This is specified in the Health and Medical Services Act (2017:30) and the Social Services Act (2001:454) with a view to meet the needs of the person. The Social Services Act (2001:454) declares that the municipality has the greatest responsibility in providing support and service in the person's everyday life. This enables the person, despite levels of health, care needs and chronological age, to live independently in a safe environment in their own home. The Patient Act [*Patientlagen*] (2014:821) provides

legislation which aims to strengthen and explain the patient's position within health care promoting integrity, self-determination and participation.

A person with dementia is also a citizen of the world with rights and obligations. The United Nations [UN] Declaration on Human Rights (1948) states each person has the: "right to life, right of security and the right of freedom" (UN, 2017). Each person has also a right for a sustainable future on earth. The UN agenda with 17 Sustainable Development Goals [SDG] for 2030 have targeted reducing inequalities for persons in society, increasing empowerment of women and children, the provision of good health care for all persons and the urgency of addressing climate change. There are three SDGs which are specifically relevant in health care: SDG #3 - Good health and well-being for all persons, SDG #5 - Gender equality and SDG #10 - Reducing inequalities in society for persons (UN, 2015).

According to the Centre for Sustainable Healthcare in Oxford (2019) health care professionals are in an ideal position to form and lead sustainable change in association with their meetings with persons in health care. By empowering persons' receiving care and applying an individual approach is beneficial in disease prevention (Centre for Sustainable Healthcare, 2019).

2.9.2 Organisation and society

Care of older persons in Sweden has over a longer period of time focused on care in the person's own home, despite potential extensive needs of health care and support (Hjalmarsen & Österman, 2017). The number of places in residential care facilities in Sweden was reduced by 24 percent during the years 2001 to 2012, while the number of older persons receiving support services in their home rose to 33 percent (Ulmanen & Szebehely, 2015). Nearly three quarters of all persons with dementia reside in their own private dwellings, a total of approximately 94,000 people (NBHW, 2012) with a rising number living on their own (Wattmo, Londos & Minthon, 2014). A large proportion of persons with dementia are cared for by family members or friends in the community (Wimo et al., 2013; Leicht et al., 2013). It is important that individualised support is offered to informal caregivers to reduce caregiver burden and help promote the well-being of both the person with dementia and their caregiver (Winblad et al., 2016). Social costs calculated for caring for persons with dementia in the community is thought to be much higher than reported, as the cost of informal care or family care is not always taken into account (Wimo et al., 2013; Leicht et al., 2013).

It is estimated, in high income countries that up to 50 percent of persons with dementia, during the disease trajectory move to residential care (Prince, Prina, & Guerchet, 2013). Due to possible challenges entailed in adjusting to new environments, persons with dementia and their families wish to remain in their own homes for as long as it is feasibly possible (Sury,

Burns & Brodaty, 2013). Home care services are vital in supporting both, the person with dementia and their partners/family members in their own homes (Low et al., 2013).

Perspectives in care, where dementia is viewed as an incapacitating disease urgently needs to be addressed with a shift of focus from the impact of debilitating symptoms towards capacities and potential of the person with dementia and their family (de Vugt & Dröes, 2017). A campaign launched by WHO (2015) urges the general public to empower persons with dementia and see them as an active citizen in society. Alzheimer's Disease International Report highlights an urgency to improve the quality of health care and social support in the community, for those living with dementia and their caregivers (Prince, 2015).

Globally dementia is “under-detected, under-diagnosed, under-disclosed, under-treated and under-managed” in primary health care (Prince et al., 2016, p. 7). Lafortune, Huson, Santi and Stolee (2015) identify a fragmented primary health care which is not user-friendly for older persons. Disclosing a major neurocognitive diagnosis to a person, in the absence of curative treatment and risks for stigmatisation, is a delicate task for physicians (Dubois et al., 2016). Physicians in primary care working with persons with dementia identify constraints in their practice which delays early detection of NPS. The physicians tended to work in a reactionary way as opposed to having a proactive approach in managing the person's symptoms. Employing a reactionary response to managing the person's symptoms entailed a stronger reliance on pharmacological management instead of applying a psychosocial approach. Constraints in practice identified were; time restraints, lack of resources and interdisciplinary teams and poor communication with community support teams (Hinton et al., 2007).

To improve the quality of the diagnosis process, management, treatment and care of persons with dementia a national Swedish Dementia Registry (SveDem) was founded (2007). Primary care and cognitive specialist clinics throughout Sweden are affiliated to the register. SveDem's annual reports facilitate health care professionals and other relevant authorities to gain insights into the current quality of care in Sweden (Religa et al., 2015).

The National Guidelines for Care of Persons with Dementia stipulates the use of a PC approach in meeting the person's care and support needs and includes regular and structured follow-ups. Social support provided should be based on the person's requests and abilities. Care planners and social workers who encounter persons with dementia, should be offered specific education in the field (NBHW, 2017). As part of the Swedish Government's (2018) work on building a national strategy of care for persons with dementia, the NBHW (2019) has created a standardised action plan. This entails that municipalities and social services offer support and care focusing on significant aspects of dementia, and the individual person's perspectives throughout the disease trajectory. The standardised action plan covers a wide range of health and social care and includes e.g. respite care, dental care and palliative care (NBHW, 2019).

2.9.3 Family member's perspective

The European Commission defines an informal caregiver as a person who assists or cares for a person with disabilities, without any formal health care education and usually without payment (Zigante, 2018). Sjöberg et al. (2020) describe how cohabitating is a protective factor for the person in developing dementia furthermore, living with a family member helps postpone admission of the person with dementia to residential care (Banerjee et al., 2003). Informal caregivers are often spouses and children to persons with dementia although friends or neighbours are also known to take on the role (Knapp, Comas-Herrera, Somani & Banerjee, 2007). It is predominantly females who take on a caring role when a family member develops dementia (Bamford et al., 2011) with gender differences existing in the experiences of caregiving (Sutcliffe et al., 2017). Hellström, Håkansson, Eriksson and Sandberg, (2017) describe how male caregivers adjust to their caring role over time, evolving from a focus on self to a collective focus. In general, an awareness is required surrounding the impact gender can have on health outcomes, social participation and support services used (Bartlett et al., 2018).

To enhance the situation for family caregivers, areas of improvement have been identified and include; resource referral, dementia education, mental health care and general medical health care (Black et al., 2013). Older caregivers' voice concerns about having plans in place if they are unable to provide care due to illness or death, however, were less likely (than younger carers) to seek support in their caring role. The level of burden in caring for a person with dementia is related to the age of the caregiver, with younger caregivers experiencing a higher level of burden of care (Greenwood, Pound, Brearley & Smith, 2019).

Caregiver burden identified by family members is related to supervision, care, time involved and assistance of the person with dementia with personal hygiene (Prince, Prina & Guerchet, 2013). Characteristics associated with caregiver burden of care included the presence of neuropsychiatric behaviours (Shankar, Hirschman, Hanlon & Naylor, 2014). For family caregivers the role of caring entails a loss of freedom often restricting their lives with no possibility for free time activities. A sense of failure can be experienced in their inability to cope with caring for a family member with dementia. Many carers neglect themselves in their caring role (Large & Slinger, 2013). Family caregivers who display symptoms of depression and are financially challenged, experience a greater burden of care (Shankar, Hirschman, Hanlon & Naylor, 2014). It is common that family caregivers to persons with dementia were depressed and prescribed anti-depressive medication (Large & Slinger, 2015). With a view to improve the situation for the family, there is a need for further knowledge of their experiences of living with a person with dementia and NPS (Moore, Ozanne, Arnes & Dow, 2013; Roche et al., 2015).

Caregiving for persons with dementia is often assumed as burdensome, this is reflected on the mainly problem-based and disease directed support which is available for couples (Bielsten et

al., 2018). Placing focus on the abilities which the person with dementia has and living in the present help caregivers in coping with the situation. Emotional and practical support from family and friends are of great importance. For many family caregivers, faith and spiritual beliefs are a source of support in their caring. When caring situations become too difficult to manage for caregivers' decisions are made about the person with dementia moving to residential care. Death is seen by some as a relief from caregiving duties, which in turn can cause mixed feelings (Large & Slinger, 2015). The National Guidelines for Dementia Care recognises, that the presence of dementia also impacts on the person's family and recommends educational programmes for family members. Further recommendations include respite care or day care for the person with dementia (NBHW, 2017).

In cases where a spouse is caring for a partner with dementia marital relationships changed, with shifts in roles together with increased responsibilities, duties and worries. The change of role from spouse to caregiver can be experienced as frustrating for some persons (Egilstrud, Bay Ravin, & Schultz Petersen, 2019). While living with this situation some couples worked on maintaining a sense of couplehood (Bergman et al., 2016; Hellström, Nolan & Lundh, 2007). The term couplehood refers to a we-identity (Kaplan et al., 1995; Hellström, Nolan & Lundh, 2007). The relationships the couples have impact on how they manage the situation. Accessible support offered to the couples mainly focuses on an individual perspective and is not relationship focused (Bielsten & Hellström, 2017).

2.9.4 The person's perspective

Living a normal autonomous life with meaning is regarded as important by persons with dementia (Von Kutzleben et al., 2012) who experience deterioration of several mental and physical abilities (Kenigsberg et al., 2016). Receiving a dementia diagnosis is often a life-changing event for the person and involves perceptions of losses both in present and future life (Robinson et al., 2011). A dementia diagnosis often entails shifts in social roles and status with some persons feeling disconnected from society and are dependent on others in activities of daily living (Eriksen et al., 2016). Social relationships with friends or family members and/or caregivers are decisive factors for maintaining a sense of self (Nordenfelt, 2010) alongside participating in meaningful activities (Han, Radel, McDowd & Sabata, 2016). Hedman, Hellström and Norberg (2019) highlight the importance of agency and communion for persons with dementia in preserving identity. According to Bakan (1996), the term agency is related to the person's autonomy and independence and the term communion is connected with desires to belong to a group.

In an article by Hazel Robinson (2017) who describes her situation: "I am a single woman of a certain age. I have Alzheimer's disease and I live alone without a carer. I manage as best I can, but I am often in terror of inevitable future deterioration" (p.14). The article goes on to explain how participation in a peer support group for persons with AD and carers empowered her as a person with AD, providing her with a "voice".

From a gender perspective, an estimated 61 percent of persons living with dementia are female which is co-related with greater life longevity in females than males (Wimo et al., 2015). Females with dementia tend to move earlier to residential care than their male peers (Bartlett, Gjernes, Lotherington & Obstefender, 2018).

Górska, Maciver and Forsyth (2019) described how persons with dementia and their family associate the presence of NPS to diminishing skills associated with the disease. With the progression of dementia this entails a wide range of skills leading to a sense of decreased competency and subsequently reduced motivation for the person with dementia. A sense of agency is experienced for the person with dementia when they feel in control and can make decisions and choices, adaption and competency play a key role in upholding agency for persons with dementia (Górska, Maciver & Forsyth, 2019).

The possibility to reside in a place of choice independently represents the wishes of many older persons, this is more so in advanced age, where the person may spend growing amounts of time in their own home environment (Fjordside & Morville, 2016; Gillsjö & Schwartz-Barcott, 2011). The desire to age in place is also relevant for persons with dementia who have special care needs, these care needs are often related to caregiver burden (Prince, Prina & Guerchet, 2013). Persons in the early stages of dementia tend to have a greater amount of unmet needs than with advanced dementia (Black et al., 2013).

A disparity in research exists surrounding perspectives of living with dementia by caregivers' perspectives outweighing the perspective of the person with dementia (Bartlett et al., 2018). The voices of older persons with impaired cognition, often deteriorating over time, are scarcely heard in research (Skovdahl & Dewing, 2017).

3 GENERAL THEORETICAL PERSPECTIVES

3.1 PERSON-CENTREDNESS

The WHO propose a People Centered Healthcare Policy Framework with a view to humanise healthcare. A person orientated healthcare system offers a well-balanced approach to meeting the needs, rights, responsibilities and capabilities of the persons and stakeholders involved (WHO, 2007).

Person-centredness has its roots in Rogerian Psychotherapy. Carl Rogers first coined the term person-centredness paving the way for the introduction of person-centred [PC] practice in therapy in 1940`s through his writings; *On becoming a person* (1961). The principles of Roger's theory are that each individual a) has considerable qualities b) can draw strength from available resources and c) can find a way to remedy difficulties. By accessing these

qualities can assist the person in maximising their potential (Rogers, 1961). PCC also has roots in nursing with Florence Nightingale, regarded as the founder of modern-day nursing. In her writings (Nightingale, 1860) highlighted the importance of promoting and involving the patient in care planning and processes. Another example from nursing is Dorethea Orem, who also focuses on the person at the centre of care and developed a self-care nursing theory (Orem, 2001).

3.1.1 Persons with dementia and personhood

A PCC approach is commonly used in caring for persons with dementia which resonates with the work of Tom Kitwood (1997), regarded as the pioneer of person-centredness in the field. The rise in PCC is deemed a response to a reductionist biomedical model approach, prioritising the basic physiological needs of persons with dementia, neglecting their psychosocial needs. These prioritisations of needs resulted in negative outcomes for the persons with dementia and their caregivers (Cheston & Bender, 1999). According to Edvardsson, Winblad and Sandman (2008) this reductionist biomedical approach essentially reduced the person with dementia to a mere bearer of an incurable disease, ignoring the personal attributes and qualities of the individual. Kitwood (1997) identified the term “malignant dispositioning” to describe when persons with dementia were treated as non-persons. Malignant dispositioning threatens the person’s dignity and sense of value (Sabat, Johnson, Swarbrick & Keady, 2011). Kitwood (1997) challenged the medical model of caring for persons with dementia and defined the term personhood as;

A status or standing bestowed upon one human being, by others, in the context of a social relationship and social being. It implies recognition respect and trust. Both the according of personhood and the failure to do so, have consequences that are empirically testable.

(Kitwood, 1997, p. 8).

The preservation of personhood is at the core of PCC, more so for persons with cognitive decline where risks of violations of rights and respect as a person exist (McCormack, 2003; Irving & Lakeman, 2010). In his work Kitwood (1997) was influenced by Buber’s (1958) philosophy on social interactions and the distinct approaches a person can have in facing the world: *I-Thou*, depicts a subject to subject relationship and *I-It* a subject to object relationship. In the *I-Thou* relationship human beings engage fully in accordance and respect in their dialog and according to Kitwood (1997) provides the framework to uphold personhood (Buber, 1970).

The concept of personhood has also been related to the *self* a person possesses. Rom Harré (1998) identified three forms of self: Self I, the singular self, with the use of terms; *I*, *me*, *mine* to describe personal attributes. Self II, the qualities held by an individual mental, physical and emotional and the beliefs the individual holds about these qualities. Self III, the

persona presented by the person who requires confirmation of others. Self III is regarded as the most vulnerable form of *self* in persons with dementia (Sabat & Collins, 1999; Sabat, 2002). Cohen-Mansfield, Golander and Arnheim (2000) describe selfhood and self-identity as synonyms to personhood. Brooker (2004) in summing up Kitwood's philosophy and key principles developed the VIPS framework of care. That persons involved in care are valued and respected, the person with dementia is offered individual care from a personal perspective and the social environment supports meetings and interactions for the person (Brooker, 2004).

3.1.2 Person-centred care framework

McCormack and McCance (2010) developed a theoretical framework for health care professionals working with PCC. The framework identifies four main constructs; Prerequisites of the health care professional (knowledge of self, professionalism, clarification of beliefs and values), Care environment (shared decision making, physical environment, skill mix) PC processes (holistic care, working with person's beliefs and values) and PC outcomes (satisfaction with care, involvement in care). The process of PCC involves working with the person's beliefs and values and forming a therapeutic presence, the term subsequently was changed to healthful relationships (McCormack & McCance, 2016).

A healthful relationship promotes the health of the person and contributes to human flourishing (McCormack & McCance, 2016) and is grounded by principles of; respect for the person (personhood), rights to self-determination and a mutual understanding and respect (McCormack, Dewing & McCance, 2011). Human flourishing is achieved (in brief) by the giving and receiving of energy, helping to create a sense of harmony. Despite it being a moral obligation to support factors which promote human flourishing, there are situations where it does not occur due to health and health care (McCormack & McCance, 2016). Vanderweele (2017) views human flourishing as broader than the psychological well-being of a person and involves other aspects of living a good life. This broader approach to human flourishing is presented under five domains, which are related to key aspects of life and if positively ranked by the person it would imply well-being. The domains are: "happiness and life satisfaction, physical and mental health, meaning and purpose, character and virtue; and close social relationships" (Vanderweele, 2017, p. 8151).

3.1.3 Components of person-centred care

The Centre for PCC at Gothenburg University [GPCC] describe PCC as a partnership between persons receiving care, their families (if relevant) and health care professionals. The following components of PCC are highlighted; Partnership, which is at the core of PCC, builds on mutual respect for each parties' knowledge about living with the disease, care, treatment and rehabilitation. To actively listen to the person's narrative in relation to their

situation. Care and support for the person is planned together and is documented in a health plan which includes goals, strategies and follow-up. Documentation in the person's medical journal is regularly updated and follows the persons through the health care chain, it includes the person's narratives and their health plan (GPCC, 2019). To implement PCC a PC culture must be in place (McCormack, McCance & Kloppe, 2017).

Integrating PC in care involves a shift from the former disease focused care to a holistic view of the person's needs. The Institute of Medicine embraces PCC, as one of the core competences of health care professionals (which includes nurses) in developing and improving health care (Institute of Medicine, 2001). The WHO (2016) recognises potential benefits of PCC in providing accessible care, health literacy and outcomes improve, patient and practitioner have greater satisfaction. This is in keeping with the National Guidelines for Dementia Care recommendations of the use of PCC in health care and social support (NBHW, 2017). Fortinsky and Down (2014) identified that a PC approach for persons with dementia is more evident in the early stages of the disease.

A PC approach focuses on the biological, social, psychological, cultural and spiritual dimensions of a person (McCormack et al., 2017).

3.1.4 Biopsychosocial dimensions and persons with dementia

The Biopsychosocial [BPS] model was designed as a reaction to the well-established bio-medical model of care which Engel regarded as too disease focused and that health and ill-health were more than the presence or absence of disease. To incorporate the person's psycho-social aspects to the bio-medical perspective entails for example including dimensions of the person's; perceptions, behaviours, feelings, social context and coping strategies help provide a holistic perspective in health care (Engel, 1977). Aging includes an objective decline of health and function however older persons, despite an objective view of ill-health, can experience both health and well-being (Molton & Jensen, 2010). The BPS model was adopted by WHO to provide a comprehensive understanding about diseases (WHO, 2002).

Cohen-Mansfield (2000) presented one of the first BPS frameworks proposing major sources of diversity in persons who develop dementia. The sources are influencing factors, lifelong events, and the existing condition. The sources in turn are comprised of three different domains; biological, psychosocial and environmental. These domains effect how dementia manifests in regard to the person's cognition, behaviour, mood and function. By identifying the sources and manifestations of these variations can influence a greater understanding of persons with dementia and improve care and interventions. Spector and Orrell (2010) built on Cohen-Mansfield's (2000) framework to highlight the importance of mental stimulation and physical environment. The revised model added MCI to the disease trajectory and they

explicitly categorised fixed and tractable factors which influenced the onset, symptoms and progression of dementia. In the BPS model described by Spector and Orrell (2010) tractable factors identified are treating disease, mood, coping strategies. The fixed factors acknowledged in the model are e.g. age, disease, education, civil status. Interventions recognised in the model include cognitive stimulation, support, hearing aids, medication. One of the goals of the BPS model is to inspire persons to see dementia as a condition which can be formed and where change, adjustment and development is possible (Spector & Orrell, 2010).

Certain aspects of living with dementia are beyond the control of the person and their surroundings whereas other areas can be stimulated and developed. The impact of the BPS factors varies throughout the disease trajectory (Spector & Orrell, 2010). Keady et al. (2012) highlight the importance of the BPS model in care of persons with dementia and include the person's physical aspects as another dimension to add to the model. As with difficulties in identifying a person's psycho-social aspects of dealing with disease, person's with dementia can experience new or worsening physical symptoms which cannot be explained from a BPS perspective.

Ghaemi (2009) questions the use of the BPS model as boundaries to the domains are unclear as BPS builds on an all-inclusivity, posing a threat to the knowledge and expertise of the health care professional. Furthermore, the model is based on an ungrounded belief and understanding that biology is a narrow concept when planning treatment (Ghaemi, 2009). Sabat (2008) agrees that a bio-medical approach is important in diagnosing dementia however social and psychological understandings of the person are also of great importance.

3.1.5 Critique of person-centred approach

PCC is not without criticism and has been described as vague, overused with differing definitions generating little impact (Brooker, 2008). Furthermore, a person's readiness to participate in a PC approach while receiving care should not be assumed (Power et al., 2020). Policies promoting PCC tend to assume that health care professionals, patients and families have realistic expectations and understandings and that the healthcare system has the resources to adapt practices accordingly (Cutler, Morecroft, Carey & Kennedy, 2019).

There are multiple conceptual definitions and approaches associated with PCC. Despite this the common principle of the philosophy is that that the older person is a unique individual with a unique biography and desires and must be considered when delivering high quality care (Edvardsson, Fetherstonhaugh & Nay, 2010). PCC has become regarded as the gold standard approach to care (Michael, Barry & Edgman-Levitan, 2012).

This doctoral thesis has embraced person-centredness in both theory and in research practice.

4 RATIONALE

Older persons with cognitive impairment are often encouraged by family, health care and society to seek a cognitive assessment, since a timely dementia diagnosis is deemed beneficial in helping the person plan for their future. Knowledge gaps exist regarding the persons' experiences of a cognitive assessment, follow-up care and receiving a neurocognitive diagnosis. Most of the available research focuses on caregiver perspectives. Older persons with cognitive impairment are under-represented in research.

The majority of persons with dementia develop NPS which increase in severity as the disease progresses, impacting greatly on the quality of life for the person and family. The presence of NPS is associated with accelerated progression of the disease for the person with earlier admission to residential care and increased healthcare costs. Capturing family members' experiences of living with a person with dementia and NPS helps gain in-depth insights into the person's situation and can help identify support needs and other factors impacting daily life. Persons with cognitive impairment also experience NPS, these symptoms are however often under-detected during a cognitive assessment. Little is known about how persons experience NPS prior to developing dementia or in the early stages of the disease trajectory. To M. Tyrrell's knowledge, routine screening for NPS is not included in a cognitive assessment in primary care and/or specialist cognitive clinics. Gaining a holistic view of the person's situation is important to help guide the person in planning future support and care while residing in the community.

5 RESEARCH AIM

5.1 GENERAL AIM

The general aim for this doctoral thesis was to describe older persons' and family members' experiences of living with cognitive impairment and related symptoms from initial cognitive assessment to living with dementia and related symptoms in a community setting.

5.2 SPECIFIC AIMS

Study I

To describe older persons who had commenced a memory assessment, experiences of living with memory impairment and related symptoms.

Study II

To describe older persons' experiences of a cognitive assessment and of exploring the presence of neuropsychiatric symptoms.

Study III

To describe spouses' experiences of living with partners who have developed neuropsychiatric symptoms related to dementia.

Study IV

To describe family members' experiences of living with persons with neuropsychiatric symptoms related to Frontotemporal dementia.

6 METHOD

The research methods in this doctoral thesis are derived from a constructivist paradigm which holds the views that there are several interpretations of reality. A constructivist paradigm is influenced by the researcher's assumptions, values and beliefs about a phenomenon (Polit & Beck, 2017).

6.1 QUALITATIVE AND PERSON-CENTRED RESEARCH

Studies I to IV are qualitative research studies. Qualitative research explores phenomena in a detailed and comprehensive way by gathering rich narrative materials using a flexible research approach (Polit & Beck, 2017). Using a qualitative inquiry contributes to research by helping persons create and connect meanings to unique experiences and develop knowledge surrounding the importance of context for the person. By gaining an understanding about how persons' experience specific aspects of life and linking this to intended and unintended outcomes reveal human phenomenon (Patton, 2015).

A PC approach was used throughout this research with a focus on connectivity with study participants. Connectivity represents efforts made to connect with self, others and contexts and is expressed in how research is carried out. Connectivity entails the following; "attentiveness and dialogue, empowerment and participation and reflexivity in the process" (Jacobs, van Lieshout, Borg & Ness, 2017, p. 52). In this research attentiveness refers to

attending to the needs, values, perspectives and wishes of participants. Dialogue with the participant, before under and after the interviews was grounded in mutual respect with focus placed on the person's voice. Furthermore, a critical approach was maintained throughout the research process which is in keeping with Jacobs, van Lieshout, Borg and Ness (2017) descriptions of connectivity.

6.2 OVERVIEW OF METHODS

Experiences of living with cognitive impairment and related symptoms from the perspectives of the person concerned and family members, have been central to this doctoral thesis.

Qualitative interviews were carried out in the studies to capture the person's experiences. An overview of the aim and method sections of each study are found in Table A.

Table A. Overview of method sections in the four studies included in this thesis

	Study I	Study II	Study III	Study IV
Aim	To describe older persons who had commenced a memory assessment, experiences of living with memory impairment and related symptoms	To describe older persons' experiences of a cognitive assessment and of exploring the presence of neuropsychiatric symptoms	To describe spouses' experiences of living with partners who have developed neuropsychiatric symptoms related to dementia	To describe family members' experiences of living with persons with neuropsychiatric symptoms related to Frontotemporal dementia
Design	Qualitative descriptive study	Qualitative descriptive follow-up interview study	Qualitative descriptive study	Qualitative descriptive study
Participants	N=23 persons commencing a cognitive assessment	N=18 persons who completed a cognitive assessment	N=14 partners to persons with NPS related to dementia	N=9 family members to persons with NPS related to FTD
Inclusion criteria	Persons ≥ 65 yrs. MMSE ≥ 15 p. commencing a cognitive assessment in primary care.	Persons ≥ 65 yrs. MMSE ≥ 15 p. who had completed a cognitive assessment in polyclinical settings	Partners to persons ≥ 65 yrs. with NPS related to dementia (AD/+ VaD)	Family members to persons ≥ 65 yrs. with NPS related to FTD
Data collection	Semi-structured Interviews	Semi-structured Interviews	Semi-structured Interviews	Semi-structured Interviews
Data analysis	Interpretive Description	Interpretive Description	Qualitative content analysis	Qualitative content analysis

6.2.1 Design

A qualitative description design was chosen for the studies as it provides a wide-ranging but rational and well-considered mix of sampling, data collection and analysis. It is an applicable design to obtain direct and mainly *unadorned* answers to areas of special interest and relevance for practitioners and organisation (Sandelowski, 2000, p. 337).

Qualitative descriptive design embraces an inductive approach, recognising the subjectivity of participants' experiences in order to develop understandings surrounding a phenomenon. The researcher is actively involved in the research process adopting an emic or insider approach gathering the data in a natural setting (Bradshaw, Atkinson & Doddy, 2017).

A purposeful sampling technique was applied in studies I to IV and involved recruitment of participants based on assumptions that they could provide rich, in-depth knowledge about the research subject under investigation (Patton, 2015; Polit & Beck, 2017). Purposeful sampling is recommended in qualitative descriptive studies (Neergaard et al., 2009; Sandelowski, 2000).

6.2.2 Study participants studies I and II

Participants 65 years and over, commencing a cognitive assessment in primary health care with Mini-Mental State Examination [MMSE] (Folstein, Folstein & McHugh, 1975) > 15 points were recruited. Participants were informed about the study by a registered district nurse or/and treating physicians at an urban primary health care centre in Sweden. The MMSE was carried out as part of the cognitive assessment in primary care with 30 points as a maximum score. The scores on the MMSE indicate a measure of levels of cognitive impairment. In association with clinical dementia ratings, Perneczky et al. (2006) describe MMSE scores of 21 to 25 points as representative of mild dementia with scores of 11 to 20 points for moderate and scores of 0 to 10 for severe dementia. In studies I to II participants with a score of 15 points or more were included, a score of 15 points is considered as a cut off point for informed consent.

The researcher M. Tyrrell followed up potential study participants with a telephone call and where interest lay, written information was posted/e-mailed to the persons concerned. After approximately one week, when the persons had time to read and reflect over their participation, M. Tyrrell followed up their decisions with a second telephone call, arranging a suitable time and place for the interview for those interested. For six participants the meeting arrangements were made via family members. In total 31 persons were contacted, eight persons declined participation stating reasons such as time restraints, lack of interest or that a family member did not want them to participate. Twenty-three persons were included in

study I, ages ranged from 70 to 91 years, seventeen males and six females, MMSE scores ranged from 16/30 to 30/30 points, eight persons lived alone, and fifteen cohabitated with a partner. All participants were residing in their own homes.

In study II a total of 18 persons were included, thirteen males and five females. Five participants from study I were not included in study II as a result of the following; two persons were not eligible to proceed with a cognitive assessment, two persons had their cognitive assessment deferred (due to medical issues) and one person who was not initially eligible later commenced an assessment, however this person did not respond to contact taken by M. Tyrrell to arrange a second interview.

6.2.3 Data collection studies I and II

Study II was a follow-up interview to study I, involving two face to face interviews with each study participant within a period of three to six months. The first interview was held with the participants at the beginning of the cognitive assessment (study I), the second interview was held upon completion of the assessment (study II).

The interviews took place during the period October 2017 to December 2018. In study I, 23 participants were interviewed and in study II, 19 participants took part in a follow-up interview. It transpired that one participant from study II, had not completed the cognitive assessment and was therefore excluded leaving a total of 18 participants. The place for all interviews was decided by the participant; the participant's own home, the researcher's workplace or at the participant's place of work. Upon permission of the participants, most interviews (studies I and II) were audio-recorded on a digital code locked device. All interviews were carried out by M. Tyrrell.

A semi-structured interview guide was used which allowed persons to respond formulating the answers in their own words in a narrative way (Polit & Beck, 2017). The opening question in study I was; *What are your reasons for seeking a memory/cognitive assessment?* One of the questions in the interview guide included reference to the NPI (Cummings et al., 1994), *Do you experience other symptoms which you can relate to memory impairment?* After the answer was provided, M. Tyrrell asked for permission to present the NPI with the list of NPS. The NPI-NH version of the NPI (Cummings et al., 1994) was used, it is a comprehensive version of NPI originally created for use in residential care. At the time of the interviews it was, to the research team's knowledge, the only NPI translated and validated into Swedish. Terminology related to residential care were avoided and replaced with terms related to a community setting. Each participant was presented with a written version of the interview guide at the beginning of the interview, for their own use. The questions were

related to experiences of living with cognitive impairment, expectations and experiences of a cognitive assessment and reporting NPS.

Seven spouses accompanied their partners to the interviews and were present during the interview session. A few spouses were occasionally invited by the study participants to join in on the interview and clarify or validate an answer which they had provided.

6.2.4 Study participants studies III and IV

In study III spouses (or in common law relationships) to persons with dementia who resided in a community setting participated. The persons with dementia were 65 years or over with a documented diagnosis of AD or VaD or combined diagnosis with BPSD (the term BPSD was used in the information letter provided to the study participants as a synonym to NPS). Most couples had been married for over 50 years and cohabitated in their own private dwelling. The spouse had good knowledge of both daytime and nighttime activities of their partner with dementia. Participants were informed about the study by staff from suburban and urban older adult clinics, a mental health unit and a dementia support organisation. After receiving names and telephone numbers of potential participants from the staff at the clinics, M. Tyrrell made telephone contact and thereafter sent written information about the study. Twenty-one participants were invited to partake in the study, seven persons declined participation stating reasons such as their partner with dementia did not wish that they participated. A total of 14 participants were included, nine females and three males, ages of participants ranged from 64 to 85 years and the persons with dementia ages ranged were between 68 to 86 years. The couples were married or in common-law relationships between 27 to 65 years.

Recruitment and interviews took place over a 12-month period; November 2014 to November 2015. The place for the interviews was left to the discretion of the participant; the participant's own home, the researcher's office or in a convenient public meeting place. Upon receiving permission from the participants, six of the interviews were audio-recorded on a code locked digital device.

In study IV family members of persons aged 65 years and older with FTD and related BPSD (NPS) were included. Two adult children and seven spouses/partners to persons with FTD were recruited to the study. Family members were informed about the study by staff from an out-patient urban geriatric clinic, an urban primary health care centre and via a notice placed in a patient support group newsletter. Family members had good knowledge of the person's (with FTD) daytime and nighttime activities. Eleven family members were approached to join the study, one person declined participation reasoning that it was too early in the person's dementia disease trajectory to share experiences. Another family member was interviewed, however the person with dementia had a mixed diagnosis of FTD and AD and therefore

excluded from the study. Of the nine participants included in the study, ages ranged from 43 to 76 years and the persons with FTD ages were between 65 to 75 years. Six females and three males participated. One spouse and adult child interviewed were related to the same person with FTD. The persons with FTD resided in their own homes, seven lived with partners and two persons lived alone. Upon receiving permission from the participants, four of the interviews were audio-recorded on a code locked digital device.

6.2.5 Data collection studies III and IV

In studies III and IV interviews were opened with information about the interview structure and an explanation of the NPI questionnaire (Cummings et al., 1994). Interviews commenced with completion of the NPI by the participant together with M. Tyrrell. Each NPS was discussed as per NPI definition and if a symptom was identified, participants were asked to rank specifics about the symptom; frequency, severity for the person with dementia and finally rank possible distress (as a family member) in the situation. Upon completion of the NPI, semi-structured interviews were carried out using an interview guide. This allowed for a more in-depth discussion about symptoms identified and included the families care and support needs with questions such as; *When your family member with dementia exhibits xxx (name of NPS) how do you manage the situation? Do you see any patterns in behaviour?*

6.2.6 Data analysis

Interpretive description

In studies I and II interpretive description [ID] (Thorne, 2016) was used to analysis the data. Thorne, Kirkham and MacDonald (1997) describe ID as a non-categorical approach to qualitative research which Thorne (2013) states leans on the “philosophical structure of applied disciplinary knowledge for its interior logic and design decisions” (p. 295).

According to Thorne (2016) the purpose of ID is threefold; to answer a real-world question, identifying empirical knowledge of the field and awareness of the contextual and conceptual *realm* of the audience (p. 40). It is a means of engaging with identifiable questions from the applied disciplines of health care departing from self-evident knowledge to a more interpretive level of knowledge. It builds on both clinical and evidence-based knowledge and creates an opportunity to identify new insights which can help shape new practices and inquiries (Thorne, 2016).

To carry out ID it is important that the study is theoretically *scaffolded* effectively. By scaffolding Thorne (2016, p. 59) refers to the positioning of the researcher on an intellectual level. That the researcher has insights to their own attributes (assumptions, beliefs values and the field of knowledge surrounding the area under investigation) and carrying out a review of

the literature in the field. Thorne (2013) describes how there are no limits to the variety of data sources which can be used to address the research question, with this in mind the NPI was included in the interview guide. In ID the researcher is advised that coding data can impede the analysis process and if used should not dominate the process. The direction the analysis takes relies on the ongoing capacity of the researcher to question the data with the growing levels of knowledge and understanding of the data (Thorne, 2013). In ID the flow of the analyses moves from what is self-evident to that which was not clearly visible, it moves back and forth from variations to similarities. During this process the researcher remains influenced by their disciplinary background in recognising what is evident and implied (Thorne, 2013).

Steps taken in data-analysis of studies I and II

Audio-recorded interviews were transcribed verbatim by M. Tyrrell and listened to again after transcription to check for accuracy of text transcriptions. In total 19 interviews were audio-recorded in study I. Notes were taken by M. Tyrrell during all interviews. Where interviews were not audio-recorded, interview text was transcribed immediately after the interview supported by the notes. The interviews were carried out in Swedish, subsequently text was then translated from Swedish to English by M. Tyrrell. The interview text was read several times to gain familiarity, focus was placed on the persons' experiences of living with cognitive impairment (study I) or of a cognitive assessment (study II). Steered by the aim of the studies interview text was identified by M. Tyrrell, this was presented to and discussed with the research team. Preliminary patterns and themes were then created in close collaboration with the research team. Thereafter patterns and themes were discussed and reviewed within the research team until a consensus was reached. A constant comparative analysis was ongoing during the data analysis process, comparing transcripts from the interviews to build findings on the emerged patterns and themes. In ID it is important not to confine the data with a premature categorisation (Thorne, 2016). Reflexibility was used during the data-analysis process.

Table B. Examples of data-analysis process in study I.

Patterns	Theme
<ul style="list-style-type: none"> - Mainly an issue for family - Memory decline a part of aging - Self and identity threatened - Social withdrawal 	<ul style="list-style-type: none"> - Viewing cognitive decline from different standpoints - Worrying about self and future

Qualitative content analysis

The academic theoretical framework for the use of qualitative content analysis in this thesis is grounded in Krippendorff's (2013) work in the area. Content analysis as described by Krippendorff (2013) is a research approach used "for making replicable and valid inferences from texts (or other meaningful matter) to the contexts of their use" (p. 24). Data is gathered at the point of departure. Content analysis as a research tool helps provide new understandings of specific phenomena which in turn can aid the development of knowledge and provide support for current practice (Krippendorff, 2013).

In qualitative content analysis coding and categorising of data plays an important role in the data analysis and is an integral part of the recommended process (Graneheim, Lindgren, & Lundman, 2017; Graneheim & Lundman, 2004). Manifest analysis and latent analysis are two approaches used in content analysis. A manifest analysis is when the researcher focuses on the actual text and the visible and apparent content. Latent analysis on the other hand focuses on interpretation and finding underlying meanings and relationships in the text. Both latent and manifest analysis require interpretation and abstraction, however the depths of interpretation and abstraction vary pending on the type of analysis chosen (Graneheim & Lundman, 2004; Graneheim, Lindgren & Lundman, 2017).

In the studies an inductive approach was used to describe phenomena and provide answers to the aims of the studies without the restraints of a theory or theoretical framework. In both studies manifest and latent approaches were used with reflexivity during the analysis cyclical process.

Steps taken in data-analysis

Interviews which were audio-recorded were transcribed verbatim by M. Tyrrell. Notes were taken during the interviews by M. Tyrrell, which assisted the transcriptions that took place directly after each interview. Transcripts were then checked for accuracy with interview notes and/or audio recorded files. Steps taken in the analysis process were inspired by Graneheim and Lundman (2004). Meaning units were identified and extracted from the data, in line with the aim of the study and thereafter condensed and organised into common categories which identified the manifest content. From the categories sub-themes and themes were created (Table C). Data-analysis was initiated by M. Tyrrell and was carried out over time as a part of a reflexivity process, in close collaboration with the research team until agreement was reached. The studies overarching themes were constructed from the sub-themes and were representative of the latent data portraying participants' experiences of living with a person with dementia and NPS.

Table C. Examples of data-analysis process in study III

Meaning units	Condensed meaning	Category	Sub-theme	Theme
<i>I am always prepared and have my bus card in my pocket and my house keys so I can get in if he locks the front door. I also have my jacket and money on standby...</i>	I have my essentials packed and am prepared to leave in a hurry	Coping with sudden unpredictable hostile events	Being prepared for sudden unpredictable events	Living on the edge, lacking support and time for self
<i>If my husband becomes violent there is no point in calling the police. I have done so several times, they can't bring him with them. When they arrive he usually has calmed down and in their eyes no crime has been committed</i>	If my husband becomes violent and I need help to protect myself, the police can't help me.	Seeking immediate assistance	Feeling vulnerable and facing domestic violence	Living on the edge, lacking support and time for self

6.3 ETHICAL CONSIDERATIONS

The studies in this doctoral thesis received ethical approval by the Regional Ethical Review Board in Stockholm, Sweden. Three supplements to the original ethical approval were sought and approved (DNR: 2014/98931). The research in this thesis project involves persons, which entails that researchers are obliged to follow certain rules of conduct. This research has been carried out in accordance with the ethical principles of research and good research practice following the Helsinki Declaration (2013) with focus on the well-being of the study participants (World Medical Association, 2013). The International Council of Nurses [ICN] code of ethics for nurses which provides a framework for standards of professional conduct was also adhered to. The ICN code states that nursing care (in this case research) should be carried out with respect for the persons and their human rights in consideration to their values, beliefs and customs (ICN, 2012).

There are four main ethical principles which are central and provide a moral framework to biomedical research, these principles are: Respect for autonomy (respect and support for self-

directed decisions), non-maleficence (avoiding harm), beneficence (providing benefit) and justice (fairness and just) (Beauchamp & Childress, 2013, p. 13).

In response to the above listed ethical principles examples are taken from the studies which represent how they were taken into consideration during the research process. Respect for autonomy - all participants in the studies were informed that their participation was voluntary and that they could at any time choose to withdraw from the study without any consequences. During the interviews M. Tyrrell was aware of maintaining the participant's personhood (Kitwood, 1997) through sympathetic presence and active listening (McCormack & McCance, 2016). In regard to non-maleficence and beneficence, many of the study participants stated that they wanted to voice their experiences with a view to help others in similar situations and improve the care and support offered to them and others. The final ethical principle of justice was applied (studies I and II) by including persons with cognitive impairment and/or neurocognitive disorders in the studies and treating all participants with respect. Malignant dispositioning (Kitwood, 1997) can occur in meetings with persons with dementia where the person is treated as part of a collective with the use of *them* (those with dementia) and *us* (healthy) scenario (Sabat, Johnson, Swarbrick & Keady, 2011). In the interviews with family members, respect was communicated about the person with dementia by seeking their consent to participate in the research interview.

Participants received oral and written information about the research study by M. Tyrrell prior to agreeing to participate. Participants in studies I and II were initially informed about the study by a district nurse or/and treating physician at the primary health care centre. As these participants were under assessment for cognitive impairment it was important that extra sensitivity was taken during the recruitment and interview process. Persons with cognitive impairment can be regarded as a vulnerable group in research and have often been excluded in earlier research. Beauchamp and Childress (2013) describe vulnerable persons in biomedical contexts as lacking abilities in safeguarding their own interests as a result of: disease, debilitation, mental illness, cognitive impairment, and other such circumstances. They advise in their text that the term vulnerable person should be used with caution due to risks of stereotyping and isolating persons (p. 91).

Beauchamp and Childress (2013) discuss the process of weighing and balancing as important in upholding the principles of biomedical ethics. With the term balancing, the authors refer to finding explanations and strengths to support beliefs about how to uphold moral norms involving deliberation and judgment. In the four studies audio recordings of interviews were planned for all participants. In studies III and IV, 10 of 23 participants (family members) agreed to the audio recording of the interviews. All of those who opted not to be recorded were spouses or partners to persons with dementia for many years. After all interviews M. Tyrrell sat aside time to ask how the study participant experienced the interview. On occasions there was a need for a therapeutic discussion, this was the case when sensitive data had been shared during the research interview.

One of the inclusion criteria in studies I and II was that participants should have a score of 15 points or over in the MMSE (Folstein, Folstein & McHugh, 1975). This commonly used objective measurement of cognitive function, not without criticism, may have excluded persons from participating in the studies. Participants with low MMSE were accompanied by their partners or family member.

In order to uphold confidentiality quotations from participants have been protected as to not reveal the identity of the person or the health care professionals involved. In some quotes, referrals to gender in regard to family members or/and staff have been made gender neutral to protect all concerned. The data gathered has been encrypted with a code list which has been stored in a separate secure place which was accessible only to members of the research group. Collected data has been stored in a secure and fireproof cabinet in keeping with regulations from Karolinska Institutet and Sophiahemmet University.

7 FINDINGS

The findings of the studies are summarised and presented below. Two studies are grouped together and presented; studies I and II followed by studies III and IV, thereafter a summary of common findings in studies I to IV.

7.1 SUMMARY OF STUDIES I AND II

Participants (persons with cognitive impairment) presented conflicting views which existed in their families regarding living with cognitive impairment and the impact it had on daily life. Participants spoke positively of their primary health care centre and GP contact. Five of twenty-three participants had self-initiated contact with their GP for a cognitive assessment, as memory decline was often viewed as part of the aging process. Most participants were encouraged by family members or others to seek a cognitive assessment and commenced a cognitive assessment to please them. A couple of participants were informed that they were not eligible to continue an assessment after the consultation appointment with their GP. The initial cognitive testing in primary care was experienced by these participants as very basic, not extensive enough to embrace their subjective cognitive concerns.

Living with cognitive impairment entailed the need to develop external and internal strategies in daily life to help recall names, places and events. Many participants had turned to technology or used other external aids to remember appointments. Other participants explained how they had created mental strategies e.g. by reducing unnecessary detail surrounding a given event, helped them to recall core features of the event. In regard to experiencing difficulty in recalling names, the ability to read cues in social interactions was important and, in some cases, the use of an endearing term could substitute a person's name.

When asked about the presence of other related symptoms to cognitive impairment few participants could identify such symptoms. Presenting the NPI during the interviews helped unveil the presence of NPS which most participants reported. These symptoms were not previously identified by the participants or discussed with others. Self-reported NPS fluctuated during the assessment process and for some NPS had disappeared upon completing the assessment. Assessing the presence of certain NPS such as hallucinations, euphoria and disinhibition evoked humorous responses from participants. Thoughts of developing such symptoms represented an inability to regulate, contrary to how they viewed themselves as persons. For others NPS reported were regarded as emotional reactions to their situation with cognitive impairment.

Undertaking a cognitive assessment was symbolic for some participants that society cared and valued them as older persons. For others, in the absence of follow-up support and/or advice, feelings of abandonment were shared after completing the assessment. In looking back over their cognitive assessments, participants experienced varying levels of trust in the process, from having trust to trust being undermined. Having trust in the process was related to confidence in an assessment process which was systematically rolled out by health care professionals with expertise in the field. For others trust was undermined after interactions with unprofessional health care personnel, experiencing the process as non-inclusive and the lack of individualised testing. Some participants felt unprepared for the assessment and receiving a neurocognitive diagnosis. Neurocognitive diagnoses such as MCI were not always disclosed by the physician in a comprehensible way, leaving participants in an ambiguous state regarding the diagnosis received. Some participants who had received a dementia diagnosis, regretted commencing the assessment in light of the diagnosis and consequences which followed. Concerns were expressed by participants about their future, both before and after the cognitive assessment.

7.2 SUMMARY OF STUDIES III AND IV

“Living with a well-known stranger” and “Living on the edge lacking support and time for self” describes how life was for family members living their lives with a person with dementia and NPS. This new form of co-existence had emerged as a result of changes (often dramatic) in the person’s personality and behaviour due to disease progression and was not representative of the person prior to developing dementia. Participants (family members) identified that the person with dementia had on average four to eight co-existing NPS, frequency, severity and distress reported varied. For persons with FTD (study IV) irritability and disinhibition followed by aggression, eating disorders and apathy were most common NPS. Irritability and apathy followed by hallucinations, aggression, anxiety and depression were the most common symptoms for persons with AD and VaD (study III).

Participants were living with unpredictable and anti-social behaviours, and in some cases domestic violence. Most families had no organised outside help or support in the home, as

support services offered did not meet the needs of the families. Social isolation was experienced by participants (mainly spouses to persons with dementia) due to anti-social behaviours and that the person with dementia could not be left alone for longer periods of time. In the event of domestic violence, calling the police for immediate assistance was not productive. When the police arrived the person with dementia was often no longer threatening and therefore no action was taken. In the face of aggression and other NPS, safety of participants and the persons with dementia were at risk. In study IV, safety threats and concerns were not only confined to real life but also on social media, as a result of inappropriate media postings by the person with FTD. Information received by participants from health care professionals about the person's diagnosis of FTD was communicated on a group level, failing to cite individual variations of the diagnosis and symptoms. This lack of knowledge in variations surrounding the impact FTD can have on a person's life resonated in the support services offered by social care planners.

7.2.1 Summary of common findings in studies I to IV

A common denominator in the four studies was the lack of an individual approach (PC) in planning care and support services for persons and family members living with neurocognitive disorders. Information provided, care planning, care packages and the cognitive assessment process were presented on a group level lacking consideration of the situation and the person or family's specific psychosocial needs.

Participants in all studies identified unmet needs such as; from the person's perspective (studies I and II), lack of follow up care or information after completing the cognitive assessment, from family member's perspective (studies III and IV) lack of relevant support in the home in relation to the presence and impact of NPS.

The use of the NPI in the interviews assisted in identifying the presence of NPS, which otherwise could go undetected for the persons concerned. Many of the persons in the studies identified that they were living with multiple NPS. Some persons, with self-reported NPS (studies I and II) viewed symptoms as emotional reactions to their situation. For family members of persons with dementia (studies III and IV) the NPI assisted in highlighting the presence and impact of NPS and mapping frequency, severity and distress caused. The level of NPS experienced by participants at the start of the cognitive assessment (study I) were higher than that when they had completed (study II). Persons with AD, VaD and FTD were reported by family members as having up to eight co-existing NPS (studies III and IV).

8 DISCUSSION

The findings presented provides insights into persons' experiences of a cognitive assessment and living with neurocognitive disorders and NPS. Persons with neurocognitive disorder and family members' experiences were investigated, though not at the same time.

8.1 DISCUSSION OF FINDINGS

The findings of the studies can be lifted into the realm of healthful relationships (within PCC) in supporting human flourishing for persons with neurocognitive disorders. Respect for personhood, Self-determination and Mutual understandings are essential domains in forming healthful relationships (McCormack & McCance, 2016; McCormack, Dewing & McCance, 2011). From the findings of this research project there are aspects in all the fore-mentioned domains which can require further attention, with a view to support human flourishing.

The main findings highlight a lack of follow-up care and psychosocial support for persons and family members living with neurocognitive disorders in a community setting. Lack of follow up care and nuances of support were identified both at the time of cognitive assessment and while living with dementia in a community setting. Care planning and support packages and the cognitive assessment process were deemed standardised and deficient of a PC, BPS approach. Family members living with persons with dementia and NPS experienced extreme expressions of NPS, in some cases jeopardising safety and welfare of all concerned. Most families (mainly couples) had no external support in the home and managed the situation themselves to the best of their abilities often leading to social isolation. Despite stark accounts of challenging and threatening situations inside and outside of the home, five of twenty-three families had home help.

A lack of mutual understanding existed between persons/family members and health care/social care planners regarding planning support and care. Many family members stated that the person with dementia had been offered instrumental support, as the person was often physically in good shape this type of support was not relevant. The Health and Medical Services Act (2017:30) and the Social Services Act (2001:454) together with the National Guidelines (NBHW, 2017) describe support as both a right and a resource however, to M. Tyrrell's knowledge types of support are not stipulated. Tardy (1985) devised a model using four categories of social support; information, emotional, instrumental and appraisal and explains how support is both given and received. The findings in this research highlight significant unmet needs of persons and family indicating the need for emotional support, appraisal and information support. These types of support were lacking for persons pre- and post-cognitive assessment and for family members living with persons with NPS. Family members explained that they mainly gained knowledge and understanding of dementia through internet searches, contacts and experiences, specific information from health care

and/or educational programmes were rarely discussed. Support highlighted in the National Guidelines for Dementia Care is in the form of day care and respite care and education for family members (NBHW, 2017).

Persons with cognitive impairment in this research were mainly encouraged by others to undertake an assessment and did so in good faith as per recommendations. Most persons in study II received an MCI diagnosis, often disclosed in an abstract way and perceived as an ambiguous diagnosis lacking follow-up support and care. This entailed that persons with MCI felt abandoned by the system and process which they had entered in good faith. Persons who experience cognitive symptoms are encouraged according to NBHW (2017) to seek a cognitive assessment. The National Guidelines for Dementia Care and the Standardised Plan of Action for care and support of persons with dementia (NBHW, 2017, 2019) focus on increasing quality of care and support for persons with dementia. However, in their endeavours, they do not appear to include care and support for persons with MCI. For some persons, MCI is a precursor to dementia (Petersen et al., 2018).

To M. Tyrrell's knowledge none of the persons with MCI received written information or follow-up visits from the specialist clinics after receiving a diagnosis. Persons who received a diagnosis of AD on the other hand, received post-assessment care and support for symptom management and treatment at the specialist clinics. Other persons with dementia (non-AD) did not appear to be eligible for such follow-up care. An inequality appears to exist in care and follow-up support for persons with neurocognitive diagnoses post-assessment. Grill et al. (2017) describe the need for practitioners to provide a written summary of the diagnosis of MCI and subsequent follow-up recommendations and identify expectations of future care. Information support can help the person process, reflect and make sense of their diagnosis and help empower the person in decision-making and in other activities. Considering the push in society (NBHW, 2017; WHO, 2019) for older persons to seek a cognitive assessment, no contingency plans seem to be in place for follow-up support for persons who receive an MCI diagnosis. The findings of this thesis highlight the need for such support.

In receiving an AD diagnosis some persons reacted with shock and regretted, with hindsight, starting the assessment process. Consequences of an AD diagnosis were overwhelming with questions arising about trusteeship and driving capabilities. Being informed of an AD diagnosis was compared to a sexual violation by one person in face of the perceived threats on autonomy and dignity. Experiences of being unprepared for the assessment and receiving a diagnosis were shared alongside needs and wishes for emotional support. Receiving a dementia diagnosis is a life-changer and communicates potential losses both present and future for the person (Robinson, et al. 2011) impacting on personhood. Being actively involved in decision making is essential in maintaining personhood and a sense of agency for persons with dementia (Fan Chung, Ellis-Hill, & Coleman, 2017). The findings in this thesis suggest the need of providing information for the person in preparation for a cognitive assessment and the likelihood of receiving a dementia diagnosis. Pre-assessment

conversation/counselling can help prepare the person emotionally and other for the upcoming assessment and possibility of receiving a diagnosis and potential impact it can have on daily life. As most persons in studies I and II were not self-referred, a pre-assessment conversation could also assist the persons in making autonomous decisions about participation. This resonates with Guss et al. (2017) who recommend pre-assessment counselling for persons commencing a cognitive assessment. As there is no present cure for dementia it is imperative, according to Posyer and Tickle (2019), to communicate hope for the future when a dementia diagnosis is disclosed to the person and family. It is important to be mindful that lacking insight and reduced initiative taking are early symptoms of dementia (APA, 2013), and can cloud decisions about seeking assistance for cognitive impairment. Upon reflection, it would be necessary to assess where the pre-assessment counselling/conversation should take place, in primary care or at the specialist clinic.

In studies I and II participants appeared to have high levels of education with many of them apprehensive about commencing a cognitive assessment. Few persons mentioned that they had a need to know if they were developing dementia or not. This is contrary to the findings of Magin et al. (2016) who explain that older persons have a desire to know if they are at risk of developing dementia. Furthermore, persons with high risk of developing dementia, with low levels of education are more apprehensive about commencing an assessment than others (Magin et al., 2016). These contradictory findings can be related to if the person is self-referred for a cognitive assessment or not, plus levels of awareness and preparedness for the assessment process.

Persons experiences of trust during the cognitive assessment process were mixed. Several persons felt valued and respected others had negative experiences of same. Experiences of respect or lack of respect during the assessment process were related to; preparedness, level of testing, encounters with health care professionals, paternalism, empathy, individualised approach and the presence of follow-up care/support. These findings are in line with Samsi et al. (2014) and Manthorpe et al. (2013) who identify that persons experience cognitive assessments as lacking a PC approach. Not all persons in studies I and II highlighted a need for a PC approach, some persons appeared satisfied and trusted that the cognitive assessment was offered in a systematic way. Power et al. (2020) highlight that PCC is based on assumptions about persons willingness to be involved in the care process and not everyone desires such involvement. Kitwood (1997) acknowledges that personhood is built on recognition and trust with failings to see the person behind cognitive decline impacting negatively on the person's view of self and feelings of respect. Requiring validation by others (self III) is the most vulnerable form of self for persons with dementia (Sabat & Collins, 1999; Sabat, 2002). Several persons in study II experienced the use of "elderspeak" (Brown & Draper, 2003), being spoken to like a child and other unprofessional encounters at the specialist clinics, which were contributing factors to feeling undermined and humiliated. These types of encounters are symbolic of an oppressive approach to care (Kitwood, 1997). These negative encounters, most likely unintentional, were reflective of an *I-it* relationship as

described by Buber (1970). Ekman, Hedman, Swedberg and Wallengren (2015) highlight how PCC is based on knowing the person, their resources and needs and seeing them as a partner in care.

Many persons in studies I and II did not view themselves as partners in care, as the cognitive assessment was often imposed on them by others and they were unprepared. Similar findings in studies III and IV describe how family members did not identify themselves as partners in care. Many felt that they were forgotten in the health and social care planning for the person with dementia. PCC is described as a partnership between persons and healthcare professionals and builds on mutual respect (GPCC, 2019). Family members also are partners in care and key facilitators in helping persons with dementia to participate in decision making activities (Fan Chung, Ellis-Hill, & Coleman, 2017) and in maintaining a sense of self (Hennelly, Cooney, Houghton & O'Shea, 2019). With the lack of support and partnership, most family members felt solely responsible for the care and wellbeing of the person with dementia. Daily life was often overshadowed by negative consequences of NPS involving disturbances in the person's thoughts, behaviours, mood and perceptions. Homes for some couples (study III) had been transformed to secure a safe environment for the person with dementia. Family members shared experiences of; keeping the home in darkness around the clock, due to the person's disturbed perceptions, fortifying the home to prevent the person with dementia for wandering and an ever preparedness for sudden violent outbursts. According to Prince, Prina and Guerchet (2013) most caregivers lack access to specialised training which could help them prevent or manage behaviours in dementia.

Standardised support packages available did not meet the real and pressing psychosocial and safety needs of family members in the face of NPS, in studies III and IV. In acute situations when the person with dementia was threatening and exhibited violent behaviour, spouses contacted emergency services for protection. Upon arrival the police were unable to intervene due to the nature of the situation. Contacting the police was often a last resort for spouses who were in fear for their life, failure to recognise their situation was symbolic of how society had failed them. As a result of these findings, members of the research team called a meeting with personnel at the Swedish Dementia Centre. By sharing our findings, we hoped to influence an on-line education course for police and security guards, which was under construction at the time (2017). This educational programme is part of the development of dementia friendly societies by the Swedish Dementia Centre (www.demenscentrum.se). In providing support for these families (couples) in studies III and IV the use of BPS model could be beneficial as a guide, in managing debilitating factors of dementia which the person and family experience (Spector & Orrell, 2010). In mental health, psychoeducation programmes are successfully used in developing knowledge and skills in problem solving for caregivers (Frias et al. 2019). This type of information and emotional support could benefit families in gaining skills to manage difficult situations arising due to the presence of NPS.

With a view to protect the person's integrity and safety in real life situations, family members often prioritised the person's safety over autonomy. The use of tracking devices was employed as a safety precaution by younger family members, without consulting the person with dementia. The balance of safety versus autonomy of persons with dementia is an ethical dilemma (Hall, Wilson, Stanmore & Todd, 2017; Landau & Werner, 2012). McCormack (2001) refers to two categories of autonomy, decisional and executorial. Decisional autonomy refers to abilities to make choices and executorial autonomy refers to the implementation these choices. Stephan et al. (2016) argues that a risk reductionist and paternalistic approach to care, with a view to keep the person safe, does not embrace the person's preferences and need for autonomy. Higgs and Gilleard (2016) discuss personhood and differentiate between the preservation of a person's moral standing and protecting a person's capabilities to perform personhood. The responsibility of upholding personhood is often shifted to others, as many persons with dementia have a decreasing lack of self-awareness and reflexivity.

The physical and psychosocial well-being of the person and family members were under threat, not only in real life but also on the internet. Close monitoring of the person's e-post correspondences and social media accounts were deemed necessary by some family members, to prevent negative outcomes. In response to misuse of social media or email correspondences by persons with dementia, one family member wished to create a filter to limit their partner's use of internet and social media. A large percent of persons between the ages of 65 to 74 use the internet daily (National Statistics UK, 2017) in the form of blogging (for persons with dementia) (Lorenz, Freddolino, Comas-Herrera, Knapp, & Damant, 2017) and Twitter use (Talbot et al., 2018). This thesis described how supporting persons and families in protecting personhood on social media appears to be a new area which requires further investigation. Braithwaite et al. (2018) highlights that with an ever-ageing population there is a need to assess usage and demands of internet technology.

Self-determination in the lives of both persons with dementia and family members was restricted in the presence of NPS e.g. anti-social behaviour. Many family members (couples) experienced social isolation. Most couples in study III were married over 50 years and appeared to have a strong sense of loyalty and respect for each other. Fan Chung, Ellis-Hill and Coleman (2017) suggest that lack of support for family caregivers can threaten their ability to maintain and respect personhood in persons with dementia. The presence of meaningful roles is important in preserving personhood for persons with dementia (Hellström, Eriksson & Sandberg, 2015). Shifts in roles within marital relationships from spouse to carer can be experienced as frustrating (Egilstrud, Bay, Ravin & Schultz Petersen, 2019). Available support offered to couples has an individual perspective and does not take the *healthy* partner into consideration (Bielsten & Hellström, 2017). Many couples, where one person has dementia work on maintaining a sense of couplehood (Bergman et al., 2016; Hellström, Nolan & Lundh, 2007).

In studies III and IV family members did not speak about timeframes regarding care and how long they could continue supporting the person with NPS. With a view to optimise care and support planning Haaksma et al. (2020) devised a tool which can assist in estimating the person's (with dementia) life expectancy. This tool can prove beneficial for both the person with dementia and family members in planning for the future. An understanding existed within the families that NPS was an integral part of the person's progressive disease, which is acknowledged by Livingston et al. (2017). Persons in the early stages of dementia also develop NPS (Osland-Vik-Mo et al., 2018). Despite recommendations of the use of validated tools during assessments to establish if the person has behavioural symptoms (Petersen et al., 2018), none of the participants (studies I and II) were assessed for NPS during the assessment. Most persons in studies I and II reported NPS, self-reported NPS were considered often as normal emotional responses/reactions to situations. Skovdahl and Dewing (2017) highlight the importance of holding a critical approach in labelling behaviour as NPS in PCC, due to risks of medicalising all types of emotional responses and behaviour when a person has dementia. Assumptions about a person's behaviour and responses are based on values and beliefs surrounding the relationship between cognition and dementia to personhood (Dewing, 2008). It is important however to be mindful that early changes in behaviour are often signs of neurodegenerative change and cognitive decline (Wahlund, Nilsson & Wallin, 2011).

The presence of NPS is the major contributing factor behind admissions of persons with dementia to full-time residential care (Toot et al., 2017; Leori et al., 2003). The move of a person with dementia to residential care causes distress for families with feelings of guilt, anger, anxiety and depression (Schultz et al., 2004; Grant et al., 2002). Early identification and treatment of NPS can help reduce cognitive deterioration and increase quality of life for the person concerned (Sachs-Ericsson & Blazer, 2015). This can enable the person with dementia to reside longer in their own home (if they so wish) and thereby contribute to a sustainable future for the person concerned.

8.2 METHODOLOGICAL CONSIDERATIONS

In this doctoral thesis four qualitative descriptive interview studies were accomplished employing two different types of data-analysis methods; interpretative description in studies I and II and qualitative content analysis in studies III and IV.

When assessing the trustworthiness in qualitative research it encompasses investigation of credibility, dependability, reliability and transferability (Lincoln & Guba, 1985). Patton (2015) refers to four elements which ascertain credibility of a qualitative study; rigorous and systematic in-depth fieldwork, systematic and thorough analysis of data, the credibility of the researcher in relation to experience and how equipped they are for the task and the research consumers appreciation of naturalistic inquiry. The credibility of a study is largely dependent on sampling participants and how the interviews are conducted. In qualitative research it is

the richness of data that is of concern as opposed to the number of participants (Polit & Beck, 2017).

In regard to the credibility of the researchers and knowledge in the field; M. Tyrrell is a registered nurse with post-graduate education in psychiatry and elderly care, with many years' experience of working with persons undergoing cognitive assessments and living with dementia. The research team have broad experiences in dementia care, nursing, medicine and qualitative research, and provided continuous support to M. Tyrrell during data collection and the data analysis process. Parallel to regular supervision sessions close contact was also maintained via email/telephone with the main supervisor.

After much deliberation within the research team a qualitative descriptive design was chosen for the four studies. It was deemed relevant in meeting the aims of the studies, which recognises the subjectivity of participant's experiences in understanding the phenomena under investigation as stated by Bradshaw, Atkinson and Doody (2016). M. Tyrrell was actively involved in the studies and could use an insider approach, when required, as per recommendations of Bradshaw, Atkinson and Doody (2017). Qualitative descriptive studies are regarded as being less theoretical than other approaches used in qualitative research (Neergaard et al., 2009). Sandelowski (2000, 2010) highlights how a descriptive approach facilitates a flexibility in relationships with theory or frameworks when planning and carrying out a study. The use of content analysis and other similar analyses methods used in descriptive studies tend to remain close to the text with a low rate of inference (Neergaard et al., 2009). According to Sandelowski (2000), this closeness to text increases the reliability of the study.

Study participants were recruited through various health care clinics and a patient support organisation. A purposeful sampling was used (Patton, 2015) which contributed to variations in ages, gender and living conditions. The initial design for studies I and II was to include both the person's and their family member's perspectives. As few participants were accompanied by family members to the interviews, the decision was taken by the research team to focus solely on the person's perspective. In studies III and IV, family members of persons with dementia with related BPSD were recruited. With the fore-mentioned inclusion criterion, participants may not be representative of all persons with dementia residing in a community setting. This in turn can impact the transferability of the findings of studies III and IV. The concept of transferability is related to the potential of extending findings to other settings or groups of persons (Polit & Beck, 2017). Lincoln and Guba (1985) highlight the researcher's responsibility to provide adequate information about the setting of the research to enable an evaluation of the flexibility of the research to other settings.

The recruitment process for studies III and IV was successful, despite encountered difficulties in recruiting study participants from multiple health care contexts, and family members to persons with specific diagnoses e.g. FTD. The recruitment process for studies I and II was

also successful and went smoothly, it was confined to one primary care centre with staff continuity and engagement in the project. The participants recruited to studies I to IV lived in urban and suburban areas of a major city in Sweden. This may affect the impact of the transferability of findings as none of the participants resided in rural areas and in participants (studies I and II) were recruited from one setting.

Kitwood (1996) highlighted being present as a “prerequisite for good caring, presentness is the quality that underlies all true relationships and every I-Thou meeting” (p. 119). With presentness in research there is a risk that the interview goes over to a therapeutic discussion, due to the nature of phenomenon under investigation. Throughout the interviews M. Tyrrell strived to maintain connectivity holding a neutral and non-judgmental approach. After concluding the interviews, time was allotted to ask participants for feedback about the interview, if required this provided an opportunity to discuss pressing issues that had arisen during the interviews. This occurred on several occasions, mainly in studies III and IV and it was important for participants, in some cases, to contact their primary health centre or their social care planner for further support.

M. Tyrrell followed-up participants after completing the assessment in study II. This allowed for a prolonged engagement, which entails longer periods of time are spent in gathering data to create an in-depth understanding of the persons’ situation under investigation. Prolonged engagement enhances the credibility of a research study according to Polit and Beck (2017). In study II most of the participants recalled the first interview (3 to 6 months beforehand), however many of the participants did not recall discussing the list of NPS from the NPI in the first interview. On a few occasions in study II participants failed to show up at the appointed time. Telephone contact was subsequently taken with participants by M. Tyrrell and new appointments were made.

The use of the NPI in the interviews (studies I to IV) may have stimulated participants to focus on symptoms which they otherwise would not have deemed problematic. On the other hand, the NPI may have assisted participants in labelling symptoms which they had not discussed before and provide an accepting climate to discuss e.g. provoking behaviours. There are in total four versions of NPI questionnaires; NPI-Ten and Twelve, NPI-Q (a brief version) and NPI-C (created for clinicians) and NPI-NH (nursing home) (www.npittest.net). The NPI-NH is a comprehensive questionnaire and was completed by the study participant under the guidance of M. Tyrrell.

In studies I and II the NPI was mainly used as a list for reporting and discussing symptoms where relevant, the frequency, severity and distress of NPS were not ranked. In designing studies III and IV the research team discussed the possibility of statistically analysing NPI measurements, however due to the limited number of participants recruited a quantitative approach was abandoned. Furthermore, a statistical analysis would not capture the unique experiences of participants and provide answers to the aims of the studies.

As previously mentioned in studies III and IV family members ranked severity, frequency and distress (as caregivers) of the NPS in the NPI (Cummings et al., 1994). Ranking caregiver distress appeared “easier” to complete for study participants as it was a subjective assessment, as opposed to ranking other areas which were related to the person with dementia. The numerical data gathered from the participants’ (studies III and IV) ranking of symptoms was included in the interview data. In studies I and II the NPI was used as a reference to provide a list and definitions of NPS which the person could report, if relevant. According to Lincoln and Guba (1985) the reliability of a study can be threatened with the use of instruments which are not robust and when insufficient analysis is carried out. The NPI is one of the most widely used validated research tool in dementia (Cummings et al., 2013; Black et al., 2009) however, most of the research is quantitative in nature. To the research team’s knowledge, it is unusual to use NPI in qualitative research.

All of the interviews were held by M. Tyrrell and data collection was completed within the timeframe for each study. This can enhance the dependability and reliability of the research. Dependability is related to the stability of the data over time and conditions (Lincoln & Guba, 1985). Reliability implies that something can be tested by reproducing and repeating the process (Lincoln & Guba, 1985). As this is qualitative research it is not possible to reproduce accurately interviews and interactions. Few participants appeared comfortable with the interviews being audio-recorded in studies III and IV, which were the first studies conducted in this project. This may have been due to several reasons such as, studies III and IV were the first interview studies in the project, M. Tyrrell was new to the participants or that participants (mainly spouses) felt that they were betraying their loyalty to partners in the interviews, and therefore did not wish to be recorded. On three occasions interviews were held in public places, if it was deemed therefore not appropriate by M. Tyrrell to audio-record the interviews, due to close proximity to other persons and conversations. During the non-recorded interviews, notes were taken by M. Tyrrell this may have in turn impacted negatively on the dependability and reliability of the interview data. Each interview was transcribed directly after each interview by M. Tyrrell to capture details of the interviews as close to real time as possible.

During the interviews, family members (studies III and IV) were respectful in their dialogues about the persons with dementia, where the person was referred to by their name or as *my wife* or *my husband*. Many of the participants had sought approval from their partners with dementia to participate in the study. There was no evidence of malignant dispositioning with the standpoint of *them* and *us* the sick and the healthy scenario (Sabat, Johnson, Swarbrick & Keady, 2011) in the dialogues.

Credibility also refers to the data-analysis process (Patton, 2015). M. Tyrrell initiated the analysis processes in the four studies followed by close collaboration with the research group, each step of the analysis process was presented and discussed with the research group. Over

time and following deliberation (with multiple drafts sent by M. Tyrrell), agreement was reached within the group regarding final sub-themes and themes, and that they were representative of the interview data gathered. R. Hedman, a senior researcher in the area of dementia, joined the research group sharing her expertise and experiences and was actively involved in the data analysis process (studies I and II).

Most participants in studies III and IV expressed the wish to help others by participating in the studies. In studies I and II some participants were hopeful that their participation could help improve the system for themselves and others. It appeared, on some occasions that it was the first time someone had shown an active interest in this aspect of the participants' lives. It was therefore of great importance to hold a balance between engagement and sympathetic presence and maintain a non-partisan approach. This can pose difficulties when narratives are stark in nature and the interview is often audio-recorded. During several interviews (studies III and IV) where information was shared about domestic violence or other information regarding sensitive issues and participants became tearful, pauses were added, M. Tyrrell gave the option for the participant to cease or defer the interview. Often the participant wished to continue with the interview with or without a pause.

Thorne (2016) highlights the need to use evaluation criteria in qualitative research which includes, representative credibility and interpretive authority. Furthermore, she states that there is also a need to go beyond the textbook concepts of evaluating credibility and assess "the moral defensibility of the research, its disciplinary relevance, pragmatic obligation and the probable truth" of the research (p. 236 - 237). Moral defensibility refers to the importance of rationale that the knowledge gained from participants is necessary and defensible and that it benefits the research area. Disciplinary relevance permeates ID and Thorne (2016) suggests that the researchers should be able to present the relevance of their research for the discipline. Pragmatic obligation means that the qualitative researcher is obliged to consider the possibility that their findings could be put into practice. Finally, Thorne (2016) states the importance of holding a critical approach in recognising that knowledge obtained is representative of probable truths which can be proved otherwise. With this applied approach to assessing credibility in qualitative research by Thorne (2016), the findings in studies I to IV present probable truths. To morally defend this research, it is required to attempt to fill knowledge gaps which currently exist. In regard to pragmatic obligation, the hope is that the findings of the studies can help somehow to improve care and support offered to persons and families living with neurocognitive disorders.

With hindsight, a longitudinal study research design could have been another option for this doctoral thesis. This would have entailed collecting data over a longer period of time as is described by Polit and Beck (2017). Following the same study participants and capturing their experiences (over several years) could provide valuable information about care and support needs during the disease trajectory.

9 SUMMARY AND CLINICAL IMPLICATIONS

“Voices to remember” is the main title of this thesis. It highlights the need for health care and society to listen to persons and family members who are impacted directly by neurocognitive disorders and related symptoms. Living with neurocognitive disorders and related symptoms often impact negatively on life. If required, a cognitive assessment is available in primary care for persons who experience cognitive decline. Society, family members and others often encourage the person to commence an assessment however, not all persons are prepared for the outcome and receiving a neurocognitive diagnosis. A pre-counselling conversation should be offered to the person prior to commencing an assessment. This can enable autonomous decisions and help prepare the person for the outcome of the assessment. Persons with MCI experience their diagnosis as abstract and ambiguous, deficient of follow-up care and support. Providing written information and a follow-up appointment for the person at the specialist clinic, after receiving a diagnosis, can help lessen uncertainties for persons concerned. An inequality appears to exist in follow-up support at the specialist clinics. Persons with AD were eligible for follow-up care however none of the other participants, with other types of neurocognitive disorders, appeared to have such follow-up. To minimise inequalities in provision of care and support all persons newly diagnosed with neurocognitive disorders should be offered follow-up support and care.

Early detection of NPS can help alleviate cognitive decline and access interventions. The use of the NPI can help persons identify the presence of symptoms which otherwise can go undetected. Not all NPS are recognised as pathological and are viewed as emotional reactions to living with cognitive impairment. Using a PC approach and focusing on the person’s BPS dimensions can help identify the person’s abilities and strengths and also needs and wishes. The well-being and safety of the person and family member can be jeopardized in the presence of NPS. Support offered to families is standardised thereby failing to focus on the family’s specific psychosocial and environmental safety needs. Family members (often spouses) are therefore often obliged to shoulder responsibilities themselves. Family members experience social isolation and feeling trapped in their situation. Support for families should be PC, tailored to their specific needs. Respect for personhood for persons with neurocognitive disorders and family members is an important aspect, which should be highlighted more in encounters with health care and in the provision of support.

9.1 FUTURE RESEARCH

The findings of the studies highlight potential areas of improvement in health care and support based on subjective accounts of persons who had experiences of neurocognitive disorders. Based on these findings here are some of my suggestions for future research;

- Implement a pre-assessment counselling conversation and evaluate the impact it has on outcomes for persons who undertake a cognitive assessment.
- Implement and evaluate a PC support programme for persons who complete a cognitive assessment and receive an MCI diagnosis. Social support offered should encompass emotional, instrumental, informational and appraisal support.
- Implement completion of the NPI (or other relevant symptom questionnaire) as a baseline investigation for persons undergoing a cognitive assessment, with organised follow-up and managing of symptoms using a BPS model in primary care.
- Assess the use of social media among persons with dementia and the possible impact it has on daily life.

10 SVENSK SAMMANFATTNING

”Röster att komma ihåg” är huvudtiteln i denna avhandlingen. Den belyser behovet av att sjukvården och samhället lyssnar på personer och familjemedlemmar som påverkas direkt av neurokognitiva sjukdomar och relaterade symtom. Att leva med neurokognitiva sjukdomar från demens till mild kognitiv svikt, och relaterade symtom, har ofta en negativ påverkan på personernas liv och deras familjemedlemmar. Primärvården erbjuder, vid behov, en kognitiv bedömning till personer som upplever subjektiv kognitiv svikt. Samhälle, familjemedlemmar och andra uppmuntrar personer att påbörja en bedömning, men inte alla som genomgår denna bedömning är beredda på resultatet, och att få t.ex. en demensdiagnos. Ett rådgivningssamtal innan personen påbörjar en utredning bör erbjudas. Detta kan möjliggöra att personen kan ta ställning till en utredning, samt att förbereda personen för resultatet. Personer som får diagnosen mild kognitiv svikt upplever att diagnosen är abstrakt och att det saknas uppföljning och stöd. Att tillhandahålla skriftlig information och ett uppföljningssamtal för personen på specialistkliniken, efter diagnos, kan bidra till att minska osäkerheten för personen och familjemedlemmarna. Det förefaller finnas en obalans i uppföljningsstöd på specialistkliniker. Det verkar som om endast personer som får en Alzheimerdiagnos är berättigade till uppföljning. För att utjämna ojämlikheter i stöd till personer som är nydiagnostiserade med neurokognitiva sjukdomar, med hjälp av ett personcentrerat förhållningssätt, bör alla personer trots diagnos erbjudas uppföljningsstöd och vård.

En stor andel av personer med demens utvecklar neuropsykiatriska symtom genom hela sjukdomsförloppet. Effekterna av dessa symptom påverkar ofta negativt personerna och deras familjer. Dessa symtom är ofta bakomliggande faktorer till varför personen flyttar till ett särskild boende. Att upptäcka neuropsykiatriska symtom tidigt kan hjälpa att lindra personens kognitiva försämring och se till att de får tillgång till stöd och vård. Det neuropsykiatriska frågeformuläret (NPI) hjälper personer att identifiera förekomsten av symtom som annars kan bli oupptäckta. Många symtom kan betraktas av personen själv som känslomässiga reaktioner på att leva med kognitiv nedsättning och att dessa symtom inte är patologiska. Att använda ett personcentrerat förhållningssätt och fokusera på personens fysiska och psykosociala aspekter kan hjälpa till att identifiera personens förmåga och behov för att hjälpa dem (eller familjen) att hantera situationen. Familjemedlemmar som lever med personer med demens och neuropsykiatriska symtom lever med otillfredsställda behov. Välbefinnandet och säkerheten för personen och familjemedlemmen äventyras ofta av symtomen. Stödet som erbjuds till familjerna verkar vara standardiserat och fokuserar inte på familjens psykosociala och miljömässiga säkerhetsbehov. Detta gör att familjemedlemmarna (ofta makar) själva axlar ansvaret. Familjemedlemmar upplever social isolering och en känsla av att vara instängda i situationen. Stöd som erbjuds familjerna bör vara personcentrerat och anpassat till deras specifika behov. Respekt (”personhood”) för personer med neurokognitiva sjukdomar och deras familjer är en viktig aspekt som bör belysas mer i den vård och det stöd som erbjuds.

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